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# Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health

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## ABSTRACT

Agency-based approaches to the health of intersex people and those with DSD focus on bodily autonomy and the cessation of normalising medical interventions until an under-age person can exercise fully informed choice regarding treatment. Discussions regarding intersex agency and health care can be inspired by the social model of health that emerged from disability theory. However, a purely social model is insufficient to address the harms that has been caused by DSD medical interventions, and the healthcare needs that some intersex people have. Drawing on original empirical research conducted in Italy, Switzerland and the UK, this article explores agency-based approaches to intersex and DSD, incorporating the social model's critique of the pathologisation of bodily diversities, whilst supporting the provision of effective healthcare where needed. The article addresses healthcare deficits and their cultural underpinnings. It identifies key impediments to intersex agency, including body normativity and sex and gender binarism. While there has been slight movement towards an agency-based approach to intersex in some national medical settings in the last ten years, there is still a need for change to the conceptualisation of intersex/DSD and subsequent revisions to healthcare provision.

## ARTICLE HISTORY

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## KEYWORDS

Intersex; DSD; social model; agency

## Introduction

Intersex can be defined as being born with bodily sex characteristics (including genitals, gonads and chromosome patterns) that do not conform to standard binary definitions of male or female bodies (OHCHR Factsheet). Critique of the medical treatment of intersex<sup>1</sup> commenced more than 30 years ago (Preves 2004). While the respective debates have grown and evolved, many contend that medical treatment itself has not shifted significantly (see Feder and Dreger 2016). Intersex stakeholder requests for change are increasingly framed in the human rights language of autonomy and bodily integrity (Crocetti et al. 2020). Agency is central to these requests.

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Discussions regarding agency and health care are inspired by the social model of health that emerged from disability theory. Critical disability theory has informed intersex rights claims from the beginning of the intersex movement (Koyama 2003). The social model of health was developed in conjunction with the social model of disability (SMD) in order to shift attention away from a pathological model of bodily difference towards the consideration of individual needs in the pursuit of a fulfilling life (Shakespeare et al. 1996).

This article develops an agency-based approach to the health of people with variations of sex characteristics (VSC). It does so by examining the key facets of an agency-based model and obstacles to its implementation. Inspiration for the article derived from reflection on the possibility of a social model of intersex health. However, as we engaged fully with the data (generated by a project that focussed on a range of stakeholder perspectives) and disability theory itself, it became apparent that a purely social model is insufficient to address the physical and emotional harm that has been caused by DSD medical intervention. Due to contentious issues of bodily and psychological harm caused by medical treatment, and the focus of DSD medical treatment in childhood, analysis must reach beyond the social factors that 'intersex' individuals (similar to the social factors that 'disable' individuals) to address the social factors that rationalise the medical negation of agency. The term 'agency-based' as used here refers to the capacity of an individual to exercise their wishes. For minors, agency refers to the protection and support of the future capacity for agency, including abstention from irreversible medically unnecessary procedures.

The biomedical treatment of intersex has been subject to criticism from intersex activists, variation-specific health advocates, medical allies, academics and International Human Rights Bodies (IHRBs). A key issue is that of unnecessary childhood genital surgeries (Monro et al. 2017), performed for socially normalising reasons<sup>2</sup>. Activists have also addressed the shame and secrecy that resulted from medical protocol (for example see Chase 1998), as well as other unnecessary socially normalising interventions (such as gonadectomies and hormone therapies) and the lack of adequate adult healthcare. IHRBs address the violation of bodily integrity and autonomy, calling aspects of current DSD medical protocol harmful cultural practices (Bauer Markus & Truffer 2020; Ghattas 2019). Intersex individuals and their families may instead only encounter a biomedical pathological framework, which focuses on modifying the form of individuals without providing agency (i.e. children; Danon 2018). Overall, intersex bodies are culturally framed as states of exception; this enables pathologisation and a dearth of intersex agency (see Davis and Murphy 2013).

## Background

The social model of disability has its roots in the activism of disabled people (UPIAS 1976) as a specific challenge to the medical model that represents disability as a result of intrinsic individualised flaws. The SMD was first developed by Oliver (1983), who argued that 'we are not disabled by our impairments but by the disabling barriers we face in society' (Oliver 2013, 1024). The model therefore challenged the medicalisation

and individualisation of disability and instead located disability at the level of social relations, including prejudice and discrimination.

Overall, the SMD seeks to challenge 'the traditional view of disability as a medical tragedy and replaces it with a view of disability as social oppression' (Shakespeare et al. 1996, 2). As Iris Marion Young (2002, xiii) argues, 'The social model of disability has enormous critical power because it shifts attention on issues of justice for people with disabilities from the "needs" of people with disabilities to others who assume that a certain background of structures and practices is [a] given'. It indicates the need for analysis of the ways that 'disability' is constructed at the levels of culture, ideology, institutions and policies (see Thomas 2005).

There is growing agreement however that the social model is not itself a comprehensive theory (Corker and Shakespeare 2002; Shakespeare and Watson 2002). Some models of disability seek to overcome the binary between social and medical models, for example the affirmation model which is diversity-positive without overlooking the lived realities of impairment (Cameron 2014). Authors such as Anastasiou and Kauffman (2013) argue that both social and medical models are reductionist; a combination of both is required.

A handful of scholars and activists have addressed the application of the social model of disability to intersex (Koyama 2003; Holmes 2008; Cornwall 2015; Carpenter 2018). Emi Koyama elaborates the application of disability theory to intersex in the following manner:

... intersex activist Esther Morris's observation that 'not having a vagina was not my problem; having to get one was', can be paraphrased to say: not having a vagina was not a disability; the social expectation that she needed to get one in order to live happy and productive life marked her body disabled. (Koyama 2006)

Holmes (2008) argues that clinical practice is still underpinned by the assumption that intersex characteristics are in themselves disabling, arguing for an assertion of difference and the refusal of clinical intervention. Differences between whether intersex is presented as 'a medical rarity that can be fixed', or an 'ordinary aspect of human diversity' (Roen 2019, 511) can greatly impact choices that are made for intersex children's bodies. Carpenter critiques the medical definition of DSD as disorder and engages a social model of disability (2018). Medical ally Wong (in Lambda Legal and InterACT 2018) suggests that discrimination and a morbid focus on sex characteristics can impede adequate healthcare provision. Cornwall argues that 'impaired bodies' and intersex bodies are both "colonised, othered and stripped of agency" (2015, 3). Sex variation-specific advocacy often reflects feminist disability theory's insistence on maintaining attention to physical suffering (French 1993; Crow 1996), as well as caution regarding the risk of 'negative socio-political shifts' (Anastasiou and Kauffman 2013).

Discussion regarding the viability of applying disability policy rights frameworks such as the Commission for the Rights of Persons with Disability (CRPD) to intersex is also taking place (Gill and Schlund-Vials 2016), but this is beyond the remit of this article. Overall, whilst a social model of intersex health is central to surfacing the cultural underpinnings of medical abuse, it is not in itself sufficient in addressing intersex health, particularly due to the disabling of healthy bodies through DSD medical treatment (such as subsequent incontinence, pain, mental health problems and sexual difficulties; see Carpenter 2018; Monro et al. 2019).

**Table 1.** Sample characteristics.

	Italy	Switzerland	UK	Totals
Intersex activists	6	2	5	13
Patient advocates	3	2	5	10
Healthcare professionals	5	2	1	8
Policy and related	1		6	7
Multi-issue groups including intersex			2	2
Totals	15	6	19	40

## Methods

We conducted qualitative research in Italy, Switzerland and the UK to gain an in-depth understanding of activist, advocate, medical and policy perspectives on intersex medical treatment and rights claims in the three case study countries. These countries were chosen due to differences in healthcare structures, activist types and national debates regarding gender.

We used documentary analysis and semi-structured interviews with intersex activists, patient advocates, and NGO and government policy makers, and healthcare practitioners, and participant observation with the activist organisation *Zwischengeschlecht*<sup>3</sup>, in order to create data regarding a range of perspectives and practice. The data that inform this article were mostly generated by 40 interviews (see [Table 1](#)) conducted between February and December 2017; the documents were referenced where documentary analysis was used.

The activists and advocates were accessed via known gatekeepers using a snowball approach. The interviews investigated the diversity of views about rights claims in healthcare settings, agendas and strategies as well as initiatives concerning VSC, perceptions of intersex activist and patient organisations, and perceptions of national, EU, and international human rights frameworks. A thematic approach (Braun, Clarke and Terry 2014) was used to analyse the material gathered through these methods. Since research participants were not familiar with the notion of agency-based approaches, questions of agency were addressed indirectly through questions regarding international human rights frameworks that focus on autonomy and bodily integrity. The analysis of an agency-based model developed inductively from the analysis of the interview data.

The research followed strict ethical guidelines which met all EU and national legal and ethics requirements. Data were anonymised except where participants wished to be named in person.

## Findings

The analysis of research findings highlights a continued lack of adequate agency-based healthcare related to two themes, or rather, two interconnected discursive and institutional nodes: the on-going pathologisation of sex variations, and the continued application of sex and gender norms. Together, these nodes serve to reproduce a model of care focussed on the bodily normalisation of subjects without agency (infants and children) and, in consequence, obstacles to medical services for those with agency (adults). Perspectives varied among stakeholders as to when, and in

which situations, individuals were entitled to agency. Significantly, while perspectives on body and gender norms varied between stakeholders and national contexts, medical perspectives on agency did not appear to vary greatly between countries (while varying greatly between stakeholders). While medical models increasingly acknowledge social and rights-based critiques (see Lee et al. 2016), it is unclear how an agency-based perspective is being applied across the board in this arena of paediatrics. Inconsistent offerings of psychological services (see Liao and Roen 2019b) and mere recommendations for a ‘cautious’ approach to early genital surgeries do not concretely embed agency in the medical model.

Despite differences in cultural discourses and institutional structures in different national contexts, little difference was found in concrete examples of practice. Heated anti-gender debates in Italy did not lend to strong differences in healthcare practitioner perspectives regarding gender normativity as a social construct. Swiss practitioners seemed more open to applying a social perspective, yet it was unclear how this has developed into an agency-based model of clinical practice. That is, parents are still legally permitted to choose irreversible unnecessary treatment for their children, as is the case in all EU nations besides Malta. None of the case study nations have country specific medical guidelines, and all healthcare participants cited the Lee et al. 2016 update to the 2006 medical consensus guidelines (Lee et al. 2006) as the closest thing to a standard of care for their centre. Lack of standardisation of practice across different DSD centres (including a lack of mandate to refer families to specialised centres) was found in all three countries. Individual practitioner perspectives on agency appear to be the primary engine shifting care norms.

### ***Agency and adequate healthcare***

Research findings highlight the fact that adequate health care for people with VSC is impeded by numerous factors: an excessive medical focus on ‘fixing’ the sexed and gendered body in childhood; the paucity of adult services and research; and ignorance and/or prejudice among medical providers. Testimonies from healthcare practitioners and activists confirmed the stark way in which the pathologisation of VSC can actually create a range of medical and other problems. An Italian DSD team member in the study stated that much of their work with adults was helping them cope with what had been done to them as children. As this same healthcare practitioner noted, other pathways are possible: ‘[the healthcare practitioners] medicalise something in order to normalise it but really you skipped the communicative, psychological, social and relational part’. Italian activist Alessandro Comeni elaborated:

He or she has an atypical genital conformation, therefore, at that time, has no illness, no life-threatening situation ... When you intervene you create a surgical wound ... you create a pathological situation and illness.

An Italian activist indicated that [a] doctor removed her gonads making her dependent on hormone therapy, and that ‘they also removed my clitoris, and practically I barely have any sensation’ (Claudia; AISIA and intersexesiste). These and other research findings are supported by the literature; unnecessary childhood procedures can be identified as the direct cause for the need for chronic medical care as well as

functional deficits. Medical interventions seek to eliminate intersex traits, yet many may feel 'intersexed', or 'disabled' by medical attention itself (Holmes 2008).

An agency-based model of health directly implies autonomy in medical choices, indicating that non-lifesaving (often cosmetic and/or unnecessary and harmful) interventions need direct consent (i.e. not proxy parental consent). People with VSC, once able to make informed decisions, may wish to receive surgical or hormonal treatment. Edited collections such as *Surgically Shaping Children* (Parens 2006) address the parallels between various types of childhood cosmetic interventions, reaching the conclusion (also elaborated by Morland 2009) that being involved in decision making (i.e. having agency) directly effects the impact these interventions have on future adults' self-esteem. In addition, participation in healthcare governance by people with VSC was identified as important by most of our interviewees (see Monro et al. 2019).

The research contributors raised a range of issues about sub-standard specialist care for people with VSC. These included fragmented care; poor medical records; a lack of care protocols; no mandate to refer patients to specialists; no mention of VSC in general medical teaching or texts; a lack of long-term health research or 'patient' directed research; a lack of funding, training, data, and personnel for care; a lack of psychological support (despite the mandate for multi-disciplinary teams including a psychologist); an absence of specialised equipment; and the need for relevant health screening (e.g. cardiac health; bone density; cancer screening). Instances of poor care were reported, for example an Italian geneticist reported a healthcare practitioner removing a child's gonads, then arriving at a different diagnosis once the genetic tests have been done. UK activists indicated a 'requirement for greater and appropriate healthcare throughout the duration of a person's life' (Holly Greenberry), that included the monitoring of health risks instead of interventions such as speculative 'preventative' gonadal removal where risk is not medically documented. Overall, there is a deficit in care, also for subjects with agency (i.e. older young people and adults).

There were some indications in the research data of prejudice among general practitioners and other staff. This may take the form of excessive attention to genital form or VSC when people seek unrelated healthcare; the confusion of intersex with LGBT or gender variation; or the request that the individual needing health care educates the healthcare provider. There was also evidence that people traumatised by insensitivity in previous medical care will not seek (or know how to advocate for) the care they need when a serious problem arises (Hall and Hall 2013; Crocetti 2013). Our data support the assertions in the literature that VSC medical examinations and treatment can be stigmatising, involving unnecessary genital display and touch. An Italian intersex activist highlighted some of the issues:

I found myself in the situation you described, having to explain things that had absolutely nothing to do with my shoulder, having to explain who intersex people are... when it's not about my shoulder, for example, but my genitals, and I might need medical care, I often decide not to go, why is that? Not only because I am not made welcome and I am immediately and automatically depersonalised... in addition to the fear that I carry with me related to the trauma I have suffered, the various traumas, because I have obviously been in contact with the healthcare environment on multiple occasions. (Alessandro Comeni)

Overall, the research findings indicated a need for agency-based care to be strengthened. In some cases, this also implied addressing the fallout from secrecy and

medical interventions themselves. This mirrors recent advocacy and activist requests (Lambda Legal and interACT 2018) for 'compassionate care'. Although these concepts regarding patients' rights are not new, they have yet to be fully applied to VSC medical treatment.

### **Body normativity and pathologisation**

One key set of cultural and institutional norms and processes that underpins the lack of agency-based care for people with VSC revolves around body normativity and pathologisation. All of the healthcare practitioners in our study acknowledged that social norms guided the rationale for normalising childhood interventions, some invoking the hypothetical future adult.

Healthcare contributors described normative parental desires as a major driver of interventions. It is likely, however, that the pathological framing that envisions these bodily differences as something to be fixed also contributes to decision making (see Streuli et al. 2013). About half of healthcare practitioners in this study indicated that they personally believed that VSC are 'normal', and developed discursive strategies (not always agency-based) to reconcile themselves with parental requests for surgeries (see also Liao et al 2019a). One Italian healthcare practitioner stated that their centre did not perform the majority of VSC surgeries, and two Swiss healthcare practitioners described their teams as emphasising delayed intervention. One mental health professional indicated that parents might see the surgeon's perspective as more authoritative and therefore follow the surgical route (see also Liao and Roen 2019b). Some healthcare practitioners placed the blame for parental desire of medical alteration on 'traditionalist' societies. However, in their own depiction of communication to patients and families, they continue to frame VSC in pathologising terms (see also Liao et al. 2019a). For example an Italian paediatric urologist termed infant sex variations as 'malformations' and reported that they described them to parents as 'incomplete development', stating:

if there are any scars I tell the child: 'I left you this mark, because when you were small you were a bit muddled [*disordinato*], your little hole for peeing was upside down, so we tidied things up a bit.

The impact of body normativity is discussed further in the literature. Danon (2018) highlights the problematic notion (within the medical model) that it is agentic to alter a child's body now, in order to obtain future gender identity or psychosocial health. As Morland (2009) pointed out, bodily alternations do not necessarily erase difference and fade from memory but can rather reinforce the idea that one's body is or was shameful. Drawing on crip theory (McRuer 2006), our findings suggest a critique of the DSD medical model as imposing 'compulsory able-bodiedness' as well as 'compulsory heterosexuality' on intersex bodies. Most of our research participants (besides two Italian and one Swiss healthcare practitioners) criticised the medical term DSD as stigmatising.

The pathologisation and stigmatisation of sex variant bodies concerns notions of 'acceptable' 'male and female' bodies. Creighton et al. (2014) describe how the determining factor in early surgeries was, until recently, the size of the phallus, as 'it was generally assumed that a boy with a small or absent penis would have poor



developmental outcomes ...' (2014, 35). Carpenter (2016) details the way in which cultural bodily norms are used to provide a rationale for medical intervention on children that 'conform to narrow social norms for females or males' (Ghattas 2013) cited in Carpenter 2016: 74). Creighton and Liao (2019) highlight how NHS Choices (in the UK) pathologises common gendered bodily variance such as breast tissue and body hair patterns, indicating that what is considered 'normal' for one gender is seen as a 'medical condition' for another.

The erasure or marginalisation of people with sex variations also emerged as issues from the research findings. Research contributors said, for instance, that '... people are treated, often, as an inconvenience, if they don't fit neatly into a male or female box, even if their medical status [is intersex], as adults' (Annie MacDonald, representative of Trans Media Watch). Contributors in both Italy and Switzerland reported that medical records had been lost or destroyed, and in Italy an activist described doctors refusing to provide access to existing files. Whilst some contributors flagged up the importance of privacy for individuals and families, it was also clear that secrecy can be problematic. For example, the UK health practitioner said that their organisation did not put information about the DSD practices on their website 'because we don't want anyone asking what we are doing! [We are] hiding!'. Another contributor highlighted that many people who have a VSC do not discuss intersex in public:

We meet up with a lot of people who are fighting to tell their story and they don't want to step up and talk about it, which is due to being told by the doctors that it's a shameful thing and that you won't fit into society. (Dawn Vago, Intersex UK)

Most contributors discussed the lack of social visibility in negative terms: it impacted on wellbeing and impeded activism to improve the lives of intersex people. Secrecy was also often combined with stigmatisation and shame. A vicious circle is evident, in which secrecy which is seen by some as necessary for liveability, but this then perpetuates cultural erasure and stigma.

### ***Sex and gender normativity***

The research showed that normativities regarding sex (physical) and gender (roles ascribed to individuals on the basis of perceived sex) formed a major impediment to agency-based approaches to intersex. As indicated elsewhere (Monro et al. 2017), many intersex people may wish to identify in a gender-normative way, but early irreversible normalising intervention limits options. As argued in the literature, the 'practices and consequences' of the medical profession actively work to align embodiment with binary constructions of sex, gender and sexuality. Ontological positions that essentialise gender, as based on sex, are used as a basis for medical interventions (Davis et al. 2016, 491). Medical interventions act to support the sex binary by making the health intersex body an 'exception' to usual medical norms, eliminating VSC traits via medical interventions, so that bodies become exclusively 'male' or 'female'.

The research findings showed that normativity concerning sex and gender was evident in all of the case study countries but was most substantially discussed by Italian contributors. Most of the Italian contributors (both activists and healthcare practitioners) described Italian culture as deeply patriarchal and gender binaried. The 'anti-

gender' movement (see Kuhar and Paternotte 2017) is making 'gender' both more known about but confused with amorphous religious-moral issues including gender roles and sexuality. Healthcare practitioners in Italy largely described society as 'not ready' for approaches that are less heavily sex-binaried. For example, an Italian paediatric endocrinologist discussed the changes in society towards being able to grow up without a defined gender but stated that 'here in Italy ... not assigning [sex] is not even an option at the moment'. Sex/gender binarism also negatively affects people with VSC in other ways. For example, a UK contributor reported that '... one of our members who had some breast development went to a hospital for a mammogram and was driven out of the waiting room by angry women' (Paul D, representative of UK patient advocacy group).

Sex and gender normativity, like bodily normativity, contribute to a slippery slope in which agency is side-lined. Several healthcare practitioner contributors displayed confusion between the request for bodily autonomy (i.e. prohibiting unnecessary interventions) and social gender requests (such as Germany's legal third gender proposal), highlighting a historical medical fixation on gender assignment, as if bodily autonomy is only an issue when the gender assignment is 'wrong'. In some cases, healthcare practitioners reiterated gender norms. For example, an Italian endocrinologist stated that in most societies there are only two gender roles and that too much freedom can cause problems [sic]. However, this perspective is contested; another Italian contributor said that: 'we're accustomed to having the genitals kind of establish gender identity, or sexual identity or role identity, but instead this is not the case, it's multifactorial', adding that healthcare practitioners, parents and some medical students still display the idea that 'normalising' treatment will lead to a 'healthy' 'binary' individual.

One of the UK patient advocates noted 'a need to expose medics to social science and feminist gender theory, so that they can appreciate the gendered/patriarchal colouring of their practices'. Intersex contributors varied in their approaches to gender diversity (see also Carpenter 2016). UK activist Joe Holliday noted that: '... in terms of intersex, you know, it's a spectrum that goes from male to female, but there's a lot in-between and most intersex people will define as male or female ...'. None of the study participants were interested in the establishment of a legal gender *just for intersex*, in line with the statement from the Third International Intersex Forum (2013)<sup>4</sup>, which advocates self-determination and multiple options.

Heterosexism, homophobia, transphobia and biphobia are intertwined with sex binarism in creating barriers to the wellbeing of intersex people. In some cases, heterosexist assumptions affected treatment norms, for example Swiss paediatrician Hans Meier noted that '... we try to understand how this person might have problems in the future with sexual intercourse', as opposed to addressing sexual pleasure (which might not include intercourse). One Italian paediatric endocrinologist discussed parental fears that a child with VSC will become a transsexual, a transvestite, 'that [the child] will go walk the streets at night as a *viado*' (in Italian usage referring to transsexual/gay male prostitute). The impact of prejudice was also noted in the UK, where an intersex representative of Trans Media Watch said that 'I think some of it [discrimination] is also based on transphobia and homophobia, which are projected onto intersex people because people don't understand intersex'.

Authors such as Feder and Dreger (2016) and Ferrara and Casper (2018) criticise the heterosexist and gender binary assumptions that underpin medical interventions on minors with DSD. As Roen et al. (2018) state, clinicians do not have standardised tools to explain variations in genital form and their potential sexual uses or even the possible negative effects of surgical maintenance and repair (Boyle et al 2005). Crip theory asks important questions regarding the places in which compulsory heterosexuality and able-bodiedness are enacted (McRuer 2006), arenas which clearly overlap in the surgical modification of functional intersex children's genital form. Santos and Santos (2018) argue that the heterosexist assumptions behind socially normative models of sexual life are ableist; they rely on notions of a valid sex life consisting of specific steps leading to penis-vagina intercourse. Some of our research contributors mirrored Hester's (2006) findings that 'healing' was more often described by individuals in terms of self-acceptance, as opposed to compliance to sex and gender norms.

Overall, the current medical model of VSC is underpinned by reductionist notions of gender, sex and sexuality. Applying an agency-based social model in healthcare settings would involve not only the development of non-discrimination policies that address sex and gender binarism and heterosexism, but also VSC specifically (see InterACT and Lambda Legal 2018), including respect for self-determination.

### ***An agency-based model?***

Overall, it appeared that there was some movement towards incorporating a social model into medical treatment in all of the case study countries, but that progress was very limited and not necessarily agency-based. There are no written guidelines for non-interventionist pathways in the three case study (or indeed most) nations (see for example Liao et al. 2015). The research findings also demonstrated considerable variation within countries and across medical teams regarding adherence to the standard biomedical approach.

The Swiss case demonstrated openness to incorporating a social model in two centres, following pressure from the activist organisation *Zwischengeschlecht*, and the NEK-CNE statement (2012). The Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE 2012) indicated that: '... irreversible sex assignment intervention involving harmful physical and psychological consequences cannot be justified' by rationale of social acceptance. An interviewed contributor to the Swiss Biomedical Ethics document specifically addressed agency:

Even if the practical side is medical, the more deeper personal side is an ethical problem; that we as adults, as doctors, as nurses, we just treat it, the babies, the young children, as we thought was right without asking them. (Judit Pok, Swiss gynaecologist)

Other contributors stressed the need to include the family in decision making, and to help them talk to the child in an age appropriate manner. Referencing differences between historical and current treatment, a Swiss medico-ethical expert suggested that mistakes had been made in the past, but that torture was never the intention. The same individual said that: 'some things were done that are very bad from our perspective now... I think our, we have learned from our experience... We're still not there and we're not perfect'. This same contributor, however, failed to support clear

prohibitions on unnecessary procedures and defended the professional medical ethics board decision not to review or revise the Swiss VSC medical protocol.

Although there has been some movement towards incorporating a social understanding of intersex in the case study countries, there are also major barriers to this shift being agency-based. Active resistance to change was revealed amongst some health practitioners, for instance a UK health professional reported one surgeon stating that he would continue to perform surgeries until legally prohibited from doing so. Some medical contributors demonstrated an emotional and normative attachment to the continuation of surgeries, for example ‘... if we go on like this I will not even be allowed to operate on a child with hypospadias. I mean, why can’t the genitals be operated on?’ (paediatric urologist 1 Italy). As the UK activist Annie Macdonald pointed out ‘[non intersex]... people are comfortable with the medical approach.’ Carpenter (2016) demonstrates the ways in which the Chicago Consensus statement recommends caution regarding medical interventions on children but nonetheless condones such interventions in relation to stigma limitation, thereby undermining consideration of agency.

## Conclusion

This article has started to develop an agency-based model of intersex health that acknowledges the health issues faced by people with VSC, and the social factors that underpin damaging medical interventions and lack of care. More research is needed however to further develop this model and to foster implementation, given the limited sample and the inductive emergence of agency as a key theme in the research findings. By centring intersex people’s agency, our discussion moves beyond both pathologisation and a reductionist social model. The article foregrounds the obstacles to the implementation of an agency-based model, including bodily sex and gender normativity. Yet, even where perspectives on conformity to bodily or gendered normativity are varied, an agency-based model is still not fully implemented in medical settings.

The issue of the agency of minors is a contentious one. Some of the healthcare practitioners in this study were not inclined to afford agency to children (in the form of postponing intervention to allow for future choices), sometimes citing national law on parental rights, concerns about parent-child relationships or traditionalist social norms. Careful support for infants and children to ensure that age-appropriate support for their agency takes place is crucial, as is the cessation of irreversible medical procedures that are not necessary for life (see Monro et al. 2017).

The lack of agency-based care pathways is a key issue (see also Creighton et al 2014). Factors that could further assist the implementation of an agency-based model include attention to the current deficits in medical care facing people with VSC, and identification of ways in which to improve care, such as more resourcing, more transparency, better communication with the patient and (if relevant) their family, the development of non-surgical pathways, and crucially, person-centred care that locates the individual with VSC at the centre of decision-making about their body. This mirrors wider discourse within activist circles. Kimberly Zieselman, (2017), an intersex woman and the executive director of *interACT: Advocates for Intersex Youth*, states ‘we want doctors to care for us, not try to ‘fix’ us’.

Our research shows that healthcare providers need to change the biomedical paradigm that underpins VSC care, not just by challenging the social underpinnings (sex, gender and bodily normativities), but by dismissing these in favour of promoting agency-based care (see also Liao et al 2019a). The biomedical paradigm frames sex variance as problematic and as located within the affected individual, rather than addressing the social forces that create stigma about sex variance and its manifestation in medical contexts. Socio-cultural perspectives are relevant to VSC; not only do forces such as body normativity, sex and gender binarism, and heterosexism create barriers to the wellbeing and even existence of people with VSC, they actually cause pathology because of the harmful effects of non-consensual early medical interventions. The currently dominant biomedical approach to VSC is based on the premise that there are a limited number of 'valid' types of body (only traditionally male and female sexed bodies), and that agency may be foregone where bodies are different. As disability scholar Scully (2002, 53) states,

Biomedical science profoundly shapes our assumptions about what a normal body is, how it should behave, when a bodily change [sic] is threatening and what the natural limitations of the body are ... Biomedicine ... accords special status to certain forms of embodiment and certain ways of knowing embodiment.

For those seeking greater wellbeing of intersex people and those with DSD, challenging this approach is crucial. Bodily, sex, and gender normativities are reflected through and perpetuated by the institution of medicine. Our research findings reveal evidence of a culture of traditionalism concerning biomedical care norms and practices, which some healthcare practitioners appeared to actively defend. This situation broadly mirrors discussions within the critical disability literature. For example, Priestley (2003) highlights the power of healthcare professionals in relation to eugenics and the termination of fetuses with congenital impairments. Some infants and children with VSC are still sterilised (see Monro et al. 2017), ostensibly to prevent future malignancies, while it is generally accepted that gonads can be monitored instead of removed. If the medical model continues to legitimise bodily modification to reduce the stigma and shame of being differently bodied without creating leeway for individual agency, a merging of social and medical models seems impossible to achieve.

Despite the dominance of the normative biomedical model, there is evidence that some healthcare practitioners are integrating social perspectives that facilitate agency. Work with families to encourage them to agree to postpone or avoid unnecessary surgical interventions is a useful example, as well as providing families with resources to help them negotiate social stigma and erasure. Some healthcare practitioners work directly with VSC activists and advocates. Intersex activists have also shifted diagnostic terrain by contesting stigmatising terms and communication (Jenkins and Short 2017). The critical disability literature highlights the utility of human rights activism for developing a separate power base from the medical profession, and in forming the public expectation of remedies to breaches of human rights (Clements and Read 2008).

A range of social factors contribute to the medicalisation of VSC, and these factors contribute to a deficit of agency. We argue that useful VSC healthcare is contingent on agency, because of (and regardless of) the social factors implicated in 'disabling' and 'intersexing' individuals.

## Notes

1. We use the terms intersex, variations of sex characteristics (VSC), Disorders (or differences) of Sex Development (DSD for disorder and dsd for differences) or 'syndrome' specific terms as the different stakeholders use them in context. However, intersex or VSC are the terms most utilised by IHRBs. For an analysis of different positions on these terms, see Jenkins and Short (2017).
2. On rare occasions, surgeries for someone with a VSC may be necessary to deal with life-threatening situations such as the inability to urinate. However, these interventions can be performed without also performing socially motivated plastic surgeries.
3. <http://zwischenengeschlecht.org/> (accessed 03.05.19).
4. <https://ilga-europe.org/what-we-do/our-advocacy-work/trans-and-intersex/intersex/events/3rd-international-intersex-forum>

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## Data availability statement

Some relevant data is available via the Intersex Human Rights and Citizenship project website, University of Huddersfield [https://research.hud.ac.uk/institutes-centres/ccid/projects/current\\_projects/](https://research.hud.ac.uk/institutes-centres/ccid/projects/current_projects/).

## References

- Anastasiou, D., and J. M. Kauffman. 2013. "The Social Model of Disability: Dichotomy Between Impairment and Disability." *The Journal of Medicine and Philosophy* 38 (4):441–459. doi: [10.1093/jmp/jht026](https://doi.org/10.1093/jmp/jht026)
- Bauer Markus, D. C., and D. Truffer. 2020. "Intersex and Human Rights." *The International Journal of Human Rights* 24 (6):724–749. doi:[10.1080/13642987.2019.1671354](https://doi.org/10.1080/13642987.2019.1671354)
- Boyle, M. E., S. Smith, and L.-M. Liao. 2005. "Adult Genital Surgery for Intersex: A Solution to What Problem?" *Journal of Health Psychology* 10 (4):573–584. doi:[10.1177/1359105305053431](https://doi.org/10.1177/1359105305053431)
- Braun, V., V. Clarke, 2014. and, and G. Terry. "Thematic Analysis." In *Qualitative Research in Clinical and Health Psychology*, edited by Rohleder Poul, and Antonia C. Lyons, 95–113. Basingstoke: Palgrave MacMillan.
- Cameron, C. 2014. "The affirmation model." In *Disability Studies: A Student's Guide*, edited by Colin Cameron, 4–7. Los Angeles: SAGE.
- Carpenter, M. 2016. "The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change." *Reproductive Health Matters* 24 (47):74–84. doi:[10.1016/j.rhm.2016.06.003](https://doi.org/10.1016/j.rhm.2016.06.003)
- Carpenter, M. 2018. "What Do Intersex People Need from Doctors?" *LGBTQIA* 20 (4):32–33. <https://www.ogmagazine.org.au/20/4-20/what-do-intersex-people-need-from-doctors/>

- Chase, C. 1998. "Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism." *GLQ: A Journal of Lesbian and Gay Studies* 4 (2):189–213. doi:10.1215/10642684-4-2-189
- Clements, L., and J. Read. 2008. "Introduction: Life, Disability and the Pursuit of Human Rights." In: *Disabled People and the Right to Life*, edited by Clements, Luke and Janet Read, 1–29. London and New York: Routledge.
- Cornwall, S. 2015. "Intersex and the Rhetorics of Disability and Disorder: Multiple and Provisional Significance in Sexed, Gender, and Disabled Bodies." *Journal of Disability & Religion* 19 (2): 106–118. doi:10.1080/23312521.2015.1010681
- Corker, M., and T. Shakespeare. 2002. "A journey around the social model." In *Disability/Postmodernity*, edited by Corker, Mairian, and Tom Shakespeare, 18–31. London: Continuum.
- Creighton, S. M., L. Michala, I. Mushtaq, and M. Yaron. 2014. "Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same?" *Psychology & Sexuality* 5 (1): 34–43. doi:10.1080/19419899.2013.831214
- Creighton, S.M. and Lih-Mei Liao (eds). 2019. *Female genital cosmetic surgery: Solution to what problem?* Cambridge: Cambridge University Press.
- Crocetti, D. 2013. *L'invisibile Intersex. Storie di Corpi Medicalizzati*. Pisa: ETS Edizioni.
- Crocetti, D., E. A. G. Arfini, S. Monro, and T. Yeardon-Lee. 2020. " 'You're basically calling doctors torturers': stakeholder framing issues around naming intersex rights claims as human rights abuses." *Sociology of Health & Illness* 42 (4):943–958. doi:10.1111/1467-9566.13072
- Crow, L. 1996. "Including All Our Lives." In *Encounters with Strangers: Feminism and Disability*, edited by Jenny Morris, 55–73. Leeds: The Disability Press.
- Danon, L. M. 2018. "Time Matters for Intersex Bodies: Between Socio-Medical Time and Somatic Time." *Social Science & Medicine* 208:89–97.
- Davis, G., and E. L. Murphy. 2013. "Intersex Bodies as a State of Exception: An Empirical Explanation for Unnecessary Surgical Modification." *Feminist Formations* 25 (2):129–152. doi: 10.1353/ff.2013.0022
- Davis, G., J. M. Dewey, and E. L. Murphy. 2016. "Giving Sex: Deconstructing Intersex and Trans Medicalization Practices." *Gender & Society* 30 (3):490–514. doi:10.1177/0891243215602102
- Feder, E., and A. Dreger. 2016. "Still Ignoring Human Rights in Intersex Care." *Journal of Pediatric Urology* 12 (6):436–437. doi:10.1016/j.jpuro.2016.05.017
- Ferrara, M., and M. J. Casper. 2018. "Genital Alteration and Intersex: A Critical Analysis." *Current Sexual Health Reports* 10 (1):1–6. doi:10.1007/s11930-018-0142-9
- French, S. 1993. *Disability, Impairment or Something In Between?* In *Disabling Barriers: Enabling environments*, edited by John Swain, Victor. Finkelstein, Sally French, and Mike Oliver, 17–25. Thousand Oaks, CA: SAGE.
- Ghattas, D. 2019. "Protecting Intersex People in Europe: A Toolkit for Law and Policymaker." Available at: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit>
- Gill, M., and C. J. Schlund-Vials. 2016. *Disability, Human Rights and the Limits of Humanitarianism*. London: Routledge.
- Hall, M. F., and S. E. Hall. 2013. "When Treatment becomes Trauma: Defining, Preventing, and Transforming Medical Trauma." *VISTA* 73:1–15.
- Holmes, M. 2008. "Mind the Gaps: Intersex and (Re-productive) Spaces in Disability Studies and Bioethics." *Journal of Bioethical Inquiry* 5 (2-3):169–181. doi:10.1007/s11673-007-9073-2
- InterACT and Lambda Legal. 2018. "Providing Ethical and Compassionate Health Care to Intersex Patients: Intersex-Affirming Hospital Policies." <https://www.lambdalegal.org/publications/intersex-affirming>
- Jenkins, T. M., and S. E. Short. 2017. "Negotiating Intersex: A Case for Revising the Theory of Social Diagnosis." *Social Science & Medicine* (1982) 175 :91–98. doi:10.1016/j.socscimed.2016.12.047
- Koyama, E. 2003. "Intersex critiques: Notes on Intersex, Disability, and Biomedical Ethics." Portland OR: Confluere Publications. <http://www.intersexinitiative.org/publications/pdf/intersexcritiques.pdf>



- Koyama, E. 2006. "From 'Intersex' to 'DSD': Toward a Queer Disability Politics of Gender." Keynote speech presented at Translating Identity conference at University of Vermont. Available at: <http://intersexinitiative.org/articles/intersectods.html>
- Kuhar, R., and D. Paternotte. 2017. *Anti-Gender Campaigns in Europe Mobilizing against Equality*. London and New York: Rowman and Littlefield International.
- Lee, P. A., C. P. Houk, S. Faisal Ahmed, I. A. Hughes, and in collaboration with the participants in the International Consensus Conference on Intersex organized by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology. 2006. "Consensus statement on management of intersex disorders." *Pediatrics* 118 (2):e488–e500. doi:10.1542/peds.2006-0738
- Lee, P. A., A. Nordenström, C. P. Houk, S. F. Ahmed, R. Auchus, A. Baratz, K. Baratz Dalke, L.-M. Liao, K. Lin-Su, L. H. J. Looijenga, the Global DSD Update Consortium, et al. 2016. "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care." *Hormone Research in Paediatrics* 85 (3):158–180., and doi:10.1159/000442975
- Liao, L.-M., D. Wood, and S. M. Creighton. 2015. "Parental Choice on Normalising Cosmetic Genital Surgery." *British Medical Journal (Clinical Research)* 351h:5124.
- Liao, L.-M., P. Hegarty, S. Creighton, T. Lundberg, and K. Roen. 2019a. "Clitoral Surgery on Minors: An Interview Study with Clinical Experts of Differences of Sex Development." *BMJ Open* 9 (6):e025821doi:10.1136/bmjopen-2018-025821
- Liao, L.-M., and K. Roen. 2019b. "The Role of Psychologists in Multi-disciplinary Teams for Intersex/Diverse Sex Development: Interviews with British and Swedish Clinical Specialists." *Psychology & Sexuality*. doi:10.1080/19419899.2019.1689158
- McRuer, R. 2006. *Crip theory: Cultural Signs of Queerness and Disability*. New York: NYU Press.
- Monro, S., D. Crocetti, T. Yeadon-Lee, F. Garland, and M. Travis. 2017. *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*. Huddersfield: University of Huddersfield Press.
- Monro, S., D. Crocetti, and T. Yeadon-Lee. 2019. "Intersex/Variations of Sex Characteristics and DSD Citizenship in the UK, Italy and Switzerland." *Citizenship Studies* (23) (8):780–797. doi:10.1080/13621025.2019.1645813
- Morland, I. 2009. "What can Queer Theory do for Intersex?" *GLQ: A Journal of Lesbian and Gay Studies* 15 (2):285–312. doi:10.1215/10642684-2008-139
- NEK-CNE Swiss National Advisory Commission on Biomedical Ethics. 2012. *On the Management of Differences of Sex Development. Ethical Issues Relating to 'Intersexuality'*. Opinion No. 20/2012. Berne: Swiss National Advisory Commission on Biomedical Ethics NEK-CNE. <https://www.apf.gov.au/DocumentStore.ashx?id=8aae774b-1b64-4ae1-947f-8ee2724ae21a>
- OHCHR. (n.d.) Fact sheet: Intersex. [https://unfe.org/system/unfe-65-Intersex\\_Factsheet\\_ENGLISH.pdf](https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf)
- Oliver, M. 1983. *Social Work with Disabled People*. Basingstoke: Palgrave Macmillan.
- Oliver, M. 2013. "The Social Model of Disability: Thirty Years On." *Disability & Society* 28 (7): 1024–1026. doi:10.1080/09687599.2013.818773
- Parens, Erik. (ed.) 2006. *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality*. Baltimore: JHU Press.
- Preves, S. E. 2004. "Out of the OR and into the Streets: Exploring the Impact of the Intersex Media Activism." *Research in Political Sociology* 13:179–223.
- Priestley, M. 2003. *Disability: A Life Course Approach*. Cambridge: Polity.
- Roen, K., S. M. Creighton, P. Hegarty, and L.-M. Liao. 2018. "Vaginal Construction and Treatment Providers' Experiences: A Qualitative Analysis." *Journal of Pediatric and Adolescent Gynecology* 31 (3):247–251. doi:10.1016/j.jpog.2018.01.001
- Roen, K. 2019. "Intersex or Diverse Sex Development: Critical Review of Psychosocial Health Care Research and Indications for Practice." *Journal of Sex Research* 56 (4-5):511–528. doi:10.1080/00224499.2019.1578331
- Santos, A. C., and A. L. Santos. 2018. "Yes, We Fuck! Challenging the Misfit Sexual Body through Disabled Women's Narratives." *Sexualities* 21 (3):303–318. doi:10.1177/1363460716688680



- Scully, J. L. 2002. "A Postmodern Disorder: Moral Encounters with Molecular Models of Disability." In *Disability/Postmodernity*, edited by Mairan Corker and Tom Shakespeare, 48–61. London: Continuum.
- Shakespeare, T., K. Gillespie-Sells, and D. Davies. 1996. *The Sexual Politics of Disability: Untold Desires*. London: Cassell.
- Shakespeare, T. W., and N. Watson. 2002. "The social model of disability: An outmoded ideology." *Research in Social Science and Disability* 2:9–28.
- Streuli, J. C., E. Vayena, Y. Cavicchia-Balmer, and J. Huber. 2013. "Shaping Parents: Impact of Contrasting Professional Counseling on Parents' Decision Making for Children with Disorders of Sex Development." *The Journal of Sexual Medicine* 10 (8):1953–1960. doi:10.1111/jsm.12214
- Third International Intersex Forum. 2013. <https://ilga-europe.org/what-we-do/our-advocacy-work/trans-and-intersex/intersex/events/3rd-international-intersex-forum>
- Thomas, C. 2005. "Developing the Social Relational in the Social Model of Disability: A Theoretical Agenda." In *The Social Model of Disability and the Majority World*, edited by Barnes, Colin, and Geoffrey Mercer, 32–47. Leeds: The Disability Press.
- UPIAS. 1976. *Fundamental Principles of Disability*. London: Union of the Physically Impaired Against Segregation.
- Young, I. M. 2002. "Foreword." In *Disability/Postmodernity*, edited by Corker Mairan and Shakespeare Tom, xii–xiv. London: Continuum.
- Zieselman, K. 2017. "US: Doctors Need Intersex Care Standards." <https://www.hrw.org/news/2017/10/26/us-doctors-need-intersex-care-standards>