

***An Invisible Public Health Crisis: The
Forced Normalization of Intersex People***

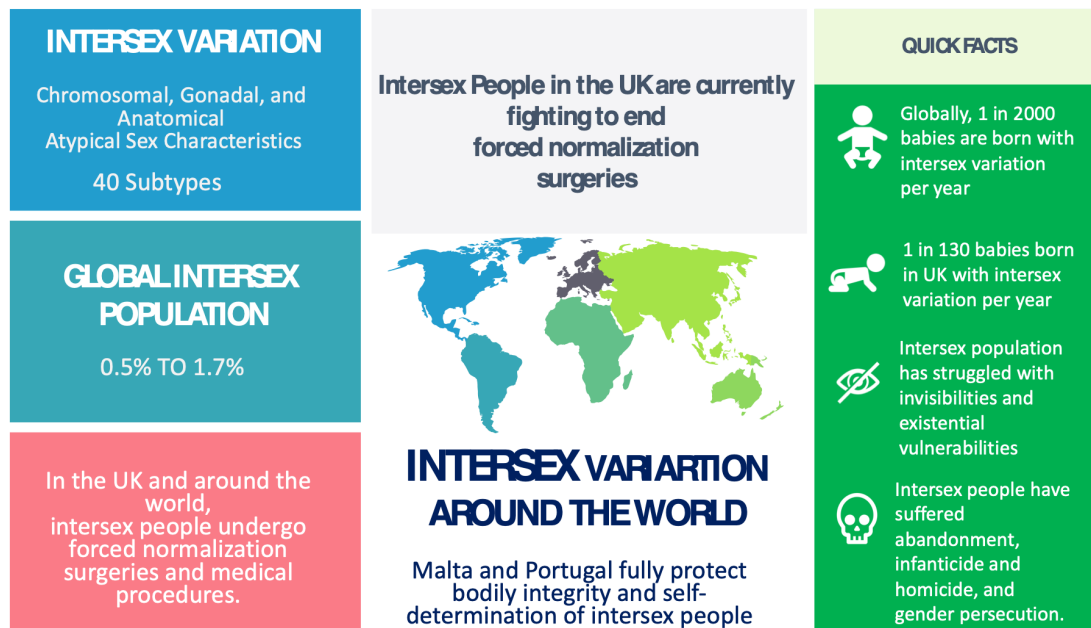


Figure 1. *Intersex Variation around the World*

ABSTRACT

Despite the burgeoning knowledge about health issues for people within the LGBTQ+ spectrum, many public health practitioners remain intellectually oblivious of the existence of the intersex community. However, in the shadows for the battle for gay marriage and transgender rights has been a quiet, yet global movement. While countries such as Portugal and Malta have given full protection to the bodily integrity and self-determination of intersex people, other countries have lagged behind. While the United Kingdom (UK) does have some anti-discrimination laws for intersex people, it presently classifies intersex people as second-class citizens. Ultimately, the UK lacks laws protecting the physical integrity and bodily autonomy of intersex bodies. This paper illuminates the public health and human rights crises of intersex people in the United Kingdom using a systems-based approach, as garnered from semi-structured interviews and secondary research. It also highlights legislative actions undertaken, as well as recommendations for future research, education, and public health policy for intersex people.

INTRODUCTION

Since 2006, intersex variation—in which the development of chromosomal, gonadal, or anatomical sex is atypical – has been characterized as *Differences of Sex Development* (Creighton, 2004; Carpenter, 2018). However, intersex bodies have been around since time immemorial (Isna.org, 2020f). Hypothesized to occur during a non-normal process of sexual development and differentiation within the womb (Isna.org, 2020a-d, i-j; see appendix). Being intersex is not identical to being transgender or transsexual; nor is it so rare as to be easily forgotten.

Estimates of intersex variation are around 0.5% to 1.7% of the global population (United Nations Human Rights, 2020). Essentially, 1 in 2,000 babies are born with ambiguously designed sexual anatomy (Altimari, 2019). As of 2017, the British Charity for DSD Families estimates that around 130 babies are born in the UK each year and need investigation for sexual assignment (Siddique, 2017). Ranging along the spectrum of genetic, chromosomal, and hormonal difference, at least 40 intersex variations have been acknowledged (Larsson, 2016). However, considerable anecdotal evidence suggest that many intersex variations are subtler, manifesting later in life (En.wikipedia.org, 2020b). Thus, the initial estimate of 1.7% of the global population may be grossly underestimated.

Intersex variations include *graduations of genital ambiguity*—such as micro-penis, clitoromegaly, partial labial fusion, delayed or absent puberty, expected changes of puberty, hypospadias, and labial or inguinal masses (Isna.org, 2020a-d, i-j).

After the 1950s, John Money's medical models of "concealment care" and "optimum gender of rearing system" were widely adopted throughout the global medical community (Isna.org, 2020f). Both intersex advocacy and medical groups point to these models as the initial medicalization of intersex people, and the springboard for normalization surgeries (Greenfield, 2014; Creighton, 2004). According to the Intersex Society of America, intersex surgeries around the world have been conducted by inferior standards for which general anatomy is *arbitrarily* and *illogically* determined and designed (Isna.org, 2020f). The rationale for normalization surgeries varies not only from country to country, but also from region to region, hospital to hospital, and doctor to doctor (Greenfield, 2014). Globally, the standard of care for intersex patients remain uneven, inadequate, and piecemeal in design (Human Rights Watch, 2017b).

The UKIA has staunchly lambasted the medical profession for stripping intersex people of both social context and autonomy vis-à-vis the medicalization process (UKIA.org, 2020). They have further objected to the clinical aura of indifference, paternalism, and ethnocentric cultural myopia toward intersex people (UKIA.org, 2020; Altimari, 2019).

INTERSEX PERSECUTION

The intersex population has often struggled with invisibilities and existential vulnerabilities. Throughout antiquity, people with intersex variation have suffered abandonment, neglect, attempted murder, infanticide and homicide, and gender persecution (Banergi, 2020; Quinn, 2019). Undergirding the perpetuation of violence against intersex people was a bulwark of cultural, religious, traditional, and medical beliefs and practices in regions throughout the globe (Astraea Lesbian Foundation for Justice, 2020).

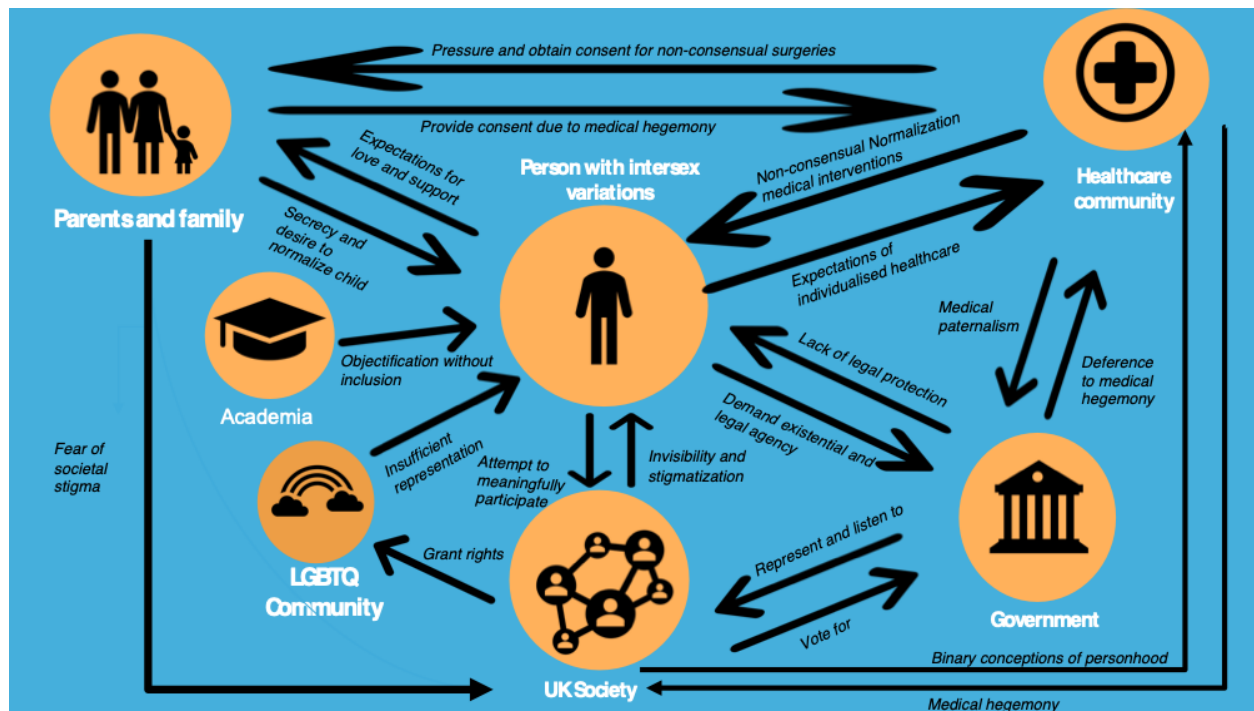


Figure 2. A Systems Perspective of the Intersex Person in the United Kingdom.

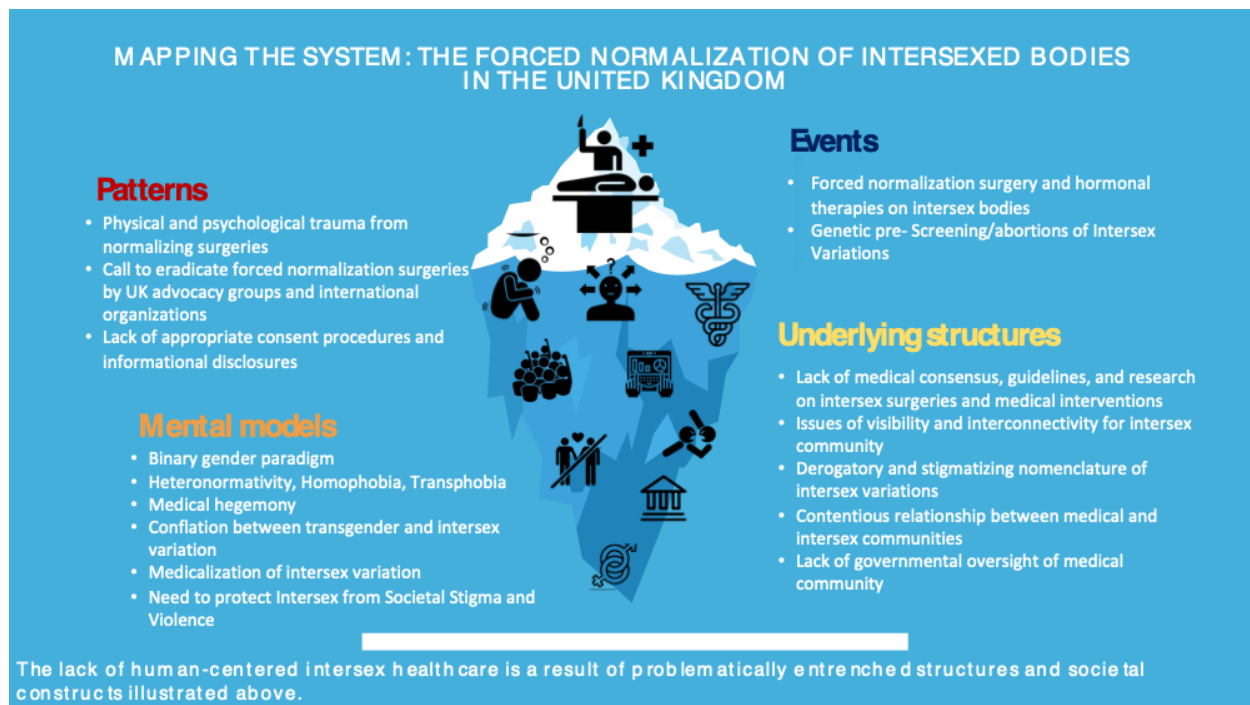


Figure 3. Iceberg System Model of Forced Normalization of Intersex Bodies in United Kingdom.

NORMALIZATION SURGERY, HORMONAL THERAPY, AND GENETIC SCREENING

To the medical community in the UK and around the world, the correction of ambiguous intersex traits (e.g., when genitalia does not appear definitively male or female) into a singular *genital* identity is referred to as “normalizing surgery” or “hormonal normalization” (Creighton, 2004; Carpenter, 2018).

Also referred to as “feminizing surgery”, “masculinizing surgery”, “genital sexing”, “surgical sexing”, and “genital re-shaping” surgery, normalizing surgery of intersex people became popular and institutionalized in the early 20th century (En.wikipedia.org, 2020b/c; Wilson, 2011). Surgeries include procedures like vaginoplasty, clitoral reduction, and gonadectomies (Guterman, 2012; Creighton, 2001). These surgeries are typically conducted on babies *under* 24 months of age (Creighton, 2001). Forced normalization of intersex people can also occur via hormonal alteration (Larsson, 2016). Of the most extreme, according to the UK Human Fertilization and Embryology Authority, forced normalization entails *genetic pre-selection* and *termination* of intersex traits that are deemed undesirable, such as Klinefelter's syndrome, 5-alpha reductase deficiency, and androgen insensitivity syndrome (En.wikipedia.org, 2020d).

But how has the system of forced normalization of intersex bodies persisted? Below, we will discuss the multidimensional nature of this crisis, with the lack of appropriate disclosure from medical personnel to patients and their families; lack of medical consensus, research, and guidelines; persisting derogatory language and minimizing attitudes; as well as heteronormativity, homophobia, and transphobia surrounding people with intersex variation.

PROBLEMS WITH PARENTAL AND PATIENT CONSENT AND INFORMATIONAL DISCLOSURES

Parents of intersex children are often given partial and pressurized information about the ‘urgent need’ for normalization surgeries and hormonal interventions (Gardiner, 2019; Barker, 2019). Some parents and intersex people even assert that the medical field outright lied to them about what surgeries they signed up for (Interview 1-3, 2020; Guterman, 2012). Within the past year, the UK intersex Association has launched a campaign against the widespread clinical practice of withholding information from intersex people regarding medical interventions and their physical and psychological implications (Strudwick, 2019).

LACK OF MEDICAL CONSENSUS, GUIDELINES, RESEARCH

The absence of medical consensus and guidelines surrounding the practice of normalization surgeries is a linchpin to the problem (Isna.org, 2020g; En.wikipedia.org, 2020b/d). Clinical consensus on normalization surgery in the UK—specifically regarding surgical timing, necessity, type of surgical intervention, and surgical criteria—is non-existent (Barker, 2019). Despite the destitution of overall care strategies, the National Health System nonetheless expressed enthusiasm and approval of normalizing surgeries on intersex bodies within the past year (Barker, 2019).

In addition, parents and intersex people continue to avow the lack of full access to medical records (Isna.org, 2020e/l). Within the UK, the medical records have been lost, disregarded, potentially destroyed, or kept hidden from intersex people (Interviewee, 2020; Barker, 2019). Coupled with the sweeping dearth of longitudinal studies and clinical trials regarding consequences of normalization surgeries on a national and global scale, evidence-based medicine regarding intersex people is minimal (Carpenter, 2018). Such scarcity of knowledge—and national commitments and international collaborations—reinforce the status quo of normalizing surgeries on intersex bodies (Larsson, 2016; Creighton, 2004).

These Informational deficiencies further contribute to a sense of invisibility, as well as personal and communal invalidation. The difficulties in establishing a larger connected intersex community in the UK are consequently magnified (Interviewee; Isna.org, 2020h).

MEDICAL LANGUAGE AND ATTITUDES

According to the UKIA, Intersex UK, and Organization Intersex International-UK, pejorative and stigmatizing language from doctors promotes normalization surgeries (En.wikipedia.org, 2020d, UKIA.org, 2020). A global and clinical consensus meeting on intersex bodies in 2005—which included two people from the intersex community and no ethicists or social scientists—cast intersex people under the umbrella term of Disorders of Sex Development, or DSD (Carpenter, 2018). However, the UKIA *unequivocally* expressed its strong disapproval and opposition to the DSD terminology since it leads to further pathologization and stigmatization of intersex people within society, and reinforced support for normalization surgeries (En.wikipedia.org, 2020d). Up until the early 20th century, intersex people were offensively referred to as hermaphrodites (Carpenter, 2018). Despite the objections of the global intersex community to current DSD terminology, there's been no attempt at change of these terms in the UK. In fact, objections have often met with medical resistance, cavalier attitudes, defensive posturing and disbelief from the medical community (UKIA.org, 2020). Thus, the language battle highlights the contentious relationship and fragmentary discourse between the intersex and medical communities (En.wikipedia.org, 2020b/d).

LACK OF GOVERNMENT INVOLVEMENT AND SUPPORT

In early 2019, despite the zeitgeist against intersex surgeries, the British government claimed it was unaware of the numbers of normalization surgeries in the country (Barker, 2019). Similarly, the British Department of Health, NHS England, and NHS digital all promulgated that they did not collate information on normalizing surgeries for intersex patients (Barker, 2019).

Like most governments, the British government grants UK physicians *carte blanche* to implement medical interventions and conduct surgeries on all patients, including intersex people (Barker, 2019). Based on historical precedent and discomfort with breaking this precedent, there appears to be no governmental oversight of, or legislative action to, the medical profession, as medicine is universally regarded as a self-regulating, self-correcting, and inherently ethical Institution (Quinn, 2019).

HETERONORMATIVITY, BINARY GENDER, HOMO- AND TRANS-PHOBIA

The desire to preserve heteronormativity and the binary gender paradigm of male and female also reinforces the existence of gender-reshaping surgeries (Wilson, 2011; Tompkins, 2017). Intersex researchers have noted parental homophobic or transphobic desires to keep their children from becoming "gay", "queer", "gender confused", or "gender-non-conforming" (Isna.org, 2020f). Common clinical goals of normalizing surgery have been to make "real

women" and "real men" who are capable of heterosexual penetrative intercourse (Human Rights Watch, 2017b; Greenfield, 2014a).

PROTECTION FROM BULLYING AND SOCIAL STIGMA

Medical practitioners and patients have also cited a keen desire to sex-surgerize their intersex children to obviate societal bullying and social stigma they may experience (Human Rights Watch, 2017b). Intersex life is believed to be difficult if atypical genitals remain unchanged (Guterman, 2012). The need to protect "social normalcy" has often been conflated with "medical necessity"(Littlefield, 2018).

CONSEQUENCES OF NORMALIZATION PROCEDURES

In 2001, however, the UK's Journal of the Royal Society of Medicine significantly interrogated "normalizing" intersex practices due to prolific claims of irreparable harm incited by the normalization surgeries (Creighton, 2001). It became abundantly clear that both a public health emergency and human rights crisis had been occurring for decades. To the intersex and global communities, normalization surgery, hormonal therapy, and genetic screen-outs of intersex variability are tantamount to infant genital mutilation and castration (Creighton, 2004; AAFP.org, 2020).

A cascade of anecdotal reports consequently revealed the multi-layered consequences of normalizing surgery. Several UK studies in the early 200s demonstrated that 28% to 46% of patients reported unsatisfactory or poor cosmetic results from normalizing surgery (Creighton, 2004). Reports published in the early 1990s reveal that normalizing surgery result in loss of sexual sensation in 20% to 50% of cases (En.wikipedia.org, 2020c). On a physical basis, intersex people who had undergone normalizing surgery were more likely to lament permanent infertility, obligatory lifelong hormonal replacement and revisional surgeries, post-operative scarring, torn genital tissue, loss of bodily integrity, pain, incontinence, and loss of sexual arousal and pleasure (Isna.org, 2020g; Carpenter, 2018; Astraea Lesbian Foundation for Justice, 2020). Psychologically, intersex people universally experienced more gender dysphoria, feelings of being assigned to the wrong gender, substance abuse, shame, confusion, suicidality, anxiety, trauma, and depression (En.wikipedia.org, 2020; Human Rights Watch, 2017a; Barker, 2019). Reports from interviewees and secondary research reveal that due to the normalization surgeries and procedures, many intersex people frequently distrust health professionals and find healthcare interactions traumatic, sometimes to the point of eschewing any medical involvement (Barker, 2019) – all of which contributes to poorly detected and ill-documented health disparities between intersex people and non-intersex people.

Resultantly, within the past 20 years, there has been a movement to review all aspects of intersex normalization procedures, including diagnostic techniques, timing and nature of surgical and medical treatments, and consent processes (Creighton, 2004). A clarion call—to end medicalization of intersex bodies, superfluous and unscrupulous normalization surgeries, hormone therapies targeting individuals with intersex variation—has echoed around the world. Alongside international human rights bodies, the UK intersex Association (UKIA) has deplored normalization procedures acts of cruelty, and violations of human rights, including freedom from torture and experimentation; right to health; right to autonomy and dignity; right to privacy; and right to bodily integrity (En.wikipedia.org, 2020d; Barkert, 2019; Isnad. Org, 2020k; Carpenter, 2018). International bodies opposing normalization surgeries on intersex bodies include organizations like the UN Human Rights Council; UN Committee on Rights of Persons with Disabilities; UN Committee Against Torture; Intersex Society of North America; Swiss National Advisory Commission on Bioethics; Council of Europe; World Health Organization; UN Office of the High Commissioner for Human Rights; and Open Society Foundations. The UN committee has even published recommendations for the provision of full, free, and, informed consent from parents and intersex people (Barker, 2019).

Several interventions have failed to protect people with intersex variations

	Intervention	Source of failure
	Policy: 2006 consensus convention guidelines	o Lack of implementation due to healthcare self-policing and entrenched views of gender binarism
	Protest action	o Action has not attracted enough mass-support because of a lack of societal allyship
	Story-telling through literature	o While this has been an effective first step, it has not scalable because of a lack of people with intersex variations in academia and a low number of parents that choose not to have their children operated on
	Relationship development between the intersex and medical communities	o Lack of shared understanding and willingness to engage. People with intersex variations typically have negative interactions with the medical community throughout their lives and the medical community subscribes to binary conceptions of personhood
	Legislation outside of the UK	o Legislation in countries such as Malta and Portugal is a step in the right direction, however due to the lack of societal change in mindsets, parents are getting normalization surgeries elsewhere

Figure 4. Failed Interventions to protect people with intersex variations.

CURRENT AND PAST INTERVENTIONS

The 2006 Consensus convention guidelines aim to create patient centered care focused on the psycho-social wellbeing of the individual. The guidelines recommend postponing surgical procedures in intersex children until they are older and in a position to make autonomous decisions about their bodies. However, *when* this decision-making ability manifests has not been delineated.

However, these guidelines have been sub-optimal because of a lack of implementation, (Monro et al, 2017) and no systems of transparency and accountability that monitor the conduct of medical professionals as it relates to people with intersex variations. These cosmetic operations are still performed because of the doctor's ability to self-police in these circumstances. Without any monitoring systems or penal mechanisms for those that violate the guidelines, medical professionals are unlikely to pivot or eradicate the status quo.

In 2015, Malta became the first country to outlaw non-consensual and medically unnecessary interventions on intersex bodies (Hay, 2015). While this legislation is groundbreaking, the terminology nonetheless “puts the impetus on the child to refuse these surgeries” (Hay, 2015). This implies that procedures should still happen. It does little to diminish the problematic perspectives against intersex traits and intersex people needing to be fixed (Hay, 2015). These changes in legislation without wholesale societal change has resulted in some Maltese parents getting the surgeries performed in different countries and even through domestic loopholes (Bauer and Truffer, 2019).

In California, a legislative proposal to ban cosmetic surgeries on intersex bodies in 2019 failed primarily due to opposition from medical bodies (Gardiner, 2019) that cited a rigid “one size fits all” solution as problematic. Even though the bill had widespread support from several civil society organisations and stakeholders including the Lesbian and Gay Medical Association, lawmakers submitted to the California Medical Associations protestations (Gardiner, 2019). Legislative change in the UK has been met with similar vociferation and resistance. Medical hegemony and embedded societal gender constructs have made the eradication of normalization surgeries a Sisyphean task.

TRANSFORMATIVE CHANGE EFFORTS

In an effort to raise awareness about intersex non-consensual surgeries, some intersex activist groups have employed protest action as a tool to pressure the medical community, lawmakers and DSD parents' groups to change surgical and hormonal normalizing practices. The protests have not typically been mass-movements due to the fragmented nature of intersex variations (e.g., Klinefelter's versus 5-alpha reductase) and comparatively low allyship relative to the gay/lesbian/bisexual rights movement. It is impossible to quantify the impact that these protests have had. However, there is minimal evidence that protestation has ignited systemic change to protect children born with intersex variations.

Building a bridge between the intersex community and the medical community has had significant challenges. A lack of shared understanding and un-willingness to engage on both sides of the aisle has often led to gridlock. Members of the intersex community cite traumas resulting from the oppressive nature of lifelong medical interactions, whilst the medical community maintains its beneficence to help intersex individuals fit into society (Knight, 2018).

VISIBILITY IN SOCIETY AND CULTURE

There is a famous quote said to film students that says, ‘If we don’t exist in culture, then you don’t exist.’ Creating space and visibility of intersex people is needed across the swathe of society – from arts and culture and media to medicine, law, and public health research. Visibility and representation of the intersex community are poignant tools, not only for advocacy, but for the recognition and validation of one’s existence.

Similar to other liberation movements, when visibility of the intersex community is attained, it is translated into political justice, then legislative action, and then the restoration of human rights.

INCLUDING THE “I” IN LGBTQ

Including the “I” in the LGBTQ is important for ally-ship and creating visibility and understanding of intersex people in the LGBTQ community. When the “I” is included, the conflation and misunderstanding of *intersex people* with *transgender or transsexual people* can begin to be unpacked and understood. More importantly, the visibility of intersex people and their specific needs can be recognized and advocated for (Munro et al, 2017).

PUBLIC HEALTH RESEARCH AND POLICY

Recognizing intersex bodies and experiences in public health research is a legitimizing force for change. Public health literature and knowledge are important tools for advocating for the right to be of intersex people. How intersex people are understood in public health literature informs how they are treated in the medical, legal and public space. We have seen the transformative and empowering force of research in feminism and the women’s rights movements through the works of Kimberle Crenshaw and Gloria Steinem, and more recently in the transgender equality movement.

Proposed solutions include funding more research on intersex experiences, as well as funding intersex people to study and pursue postgraduate degrees. Projects such as the *Intersex: New Interdisciplinary Approaches (INIA)* –which fund early-stage researchers from the European Union to pursue doctorates relating to the physical, psychological, and emotional health of intersex people (University of Huddersfield, 2019)—are important projects that need to be amplified and replicated at scale.

Furthermore, there needs to be a simultaneous demand for updated and evidence-based clinical research on the best medical, surgical, and psychological care for intersex people. Ample

research and education will help to pave the way for much needed policy around the human and health rights of intersex people.

CONCLUSION

The recognition and rectification of the invisible public health and human rights emergencies against intersex people is of paramount importance. Whilst this paper has focused on issues of intersex rights within the UK, the issues are global in scale. Just as the public health practitioner and social justice advocate seeks to eradicate racism, sexism, ableism, homophobia and transphobia as determinants of health, so should they seek to eliminate the forced normalization of intersex bodies and its devastating impacts on their physical, psychological, and emotional health.

APPENDIX

Interviews conducted on March 12, 2020, March 14, 2020, and March 17, 2020.

Interviewee	Qualification
1	Intersex activist and human rights campaigner in the UK.
2	Intersex individual with hypospadias variation
3	Intersex individual with MRKH variation (Mayer-Rokitansky-Kuster-Hauser syndrome)
4	Intersex individual with Swyer's Syndrome variation
5	Intersex individual with Androgen Insensitivity Syndrome variation
6	Intersex individual with Klinefelter's syndrome
7	Professional expert in intersex health, law, and social justice

Table 1. List of Interviewees

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