



Article

# Cultural Awareness of Intersex in Malta: Invisibility, Stigma and Epistemic Injustice

Claudia Bartolo Tabone <sup>1</sup>, Fae Garland <sup>2,\*</sup> and Mitchell Travis <sup>3</sup>

- Department of Moral Theology, Faculty of Theology, University of Malta, MSD 2080 Msida, Malta; claudia.bartolo.99@um.edu.mt
- <sup>2</sup> Law Department, University of Manchester, Manchester M13 9PL, UK
- School of Law, University of Leeds, Leeds LS2 9JT, UK; m.travis@leeds.ac.uk
- \* Correspondence: fae.garland@manchester.ac.uk

Abstract: In 2015, Malta introduced ground-breaking legal reform designed to protect the bodily integrity of intersex infants in Malta. Drawing on semi-structured interviews with healthcare professionals, lawyers, policy-makers and advocates, this article considers the extent to which this reform has improved the cultural visibility and recognition of intersex people in Malta. Engaging with literature on epistemic injustice, this article provides new evidence for a cultural silence around intersex bodies that operates not only at a level of public knowledge but also at the individual and institutional levels. Our findings relate to three categories of visibility: political, cultural and medical. While the political visibility of intersex was an important factor in the introduction and shape of law reform in Malta, our respondents felt that the legislation had had very little effect on public understandings and familiarity with intersex issues. Moreover, respondents felt that many intersex people would be unlikely to know that they were intersex due to the limited conceptual and critical resources available to them: issues such as stigma and shame further encourage the epistemic silencing of intersex issues. The lack of cultural and medical visibility has significantly limited both the intended and hoped-for effect of the legislation. The article considers the broader implications of these results beyond Malta for those seeking to use the law to improve the lived experiences of intersex people.

Keywords: intersex; variations of sex characteristics; DSD; epistemic injustice; Malta; law; cultural visibility



Citation: Bartolo Tabone, Claudia, Fae Garland, and Mitchell Travis. 2024. Cultural Awareness of Intersex in Malta: Invisibility, Stigma and Epistemic Injustice. *Social Sciences* 13: 150. https://doi.org/10.3390/ socsci13030150

Academic Editor: Nigel Parton

Received: 26 January 2024 Revised: 28 February 2024 Accepted: 29 February 2024 Published: 6 March 2024



Copyright: © 2024 by the authors. Licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license (https://creativecommons.org/licenses/by/4.0/).

### 1. Introduction

In 2015, Malta introduced ground-breaking legal reform through its Gender Identity, Gender Expression and Sex Characteristics Act 2015 (GIGESCA) which was designed to protect the bodily integrity of intersex infants. In doing so, Malta became the first jurisdiction to introduce a legislative framework that ostensibly challenged medical practice by prohibiting unnecessary medical interventions on children without their consent. This article arises from the first small-scale qualitative study with policy-makers and healthcare professionals<sup>1</sup> to provide evidence uncovering the effect of this legislation on intersex rights. One of the hoped-for consequences of GIGESCA was not only to directly change medical practice, but to help bring about wider cultural visibility and recognition of intersex people in Malta (Garland and Travis 2018) and, in doing so, reduce stigma and experiences of epistemic injustice. This article examines the extent to which this legislation has brought about such change in Malta. Such examination is integral for a broader understanding of the efficacy of legal reform, as Malta's experience demonstrates how state failure to recognise and redress epistemic injustice through other mechanisms can render legislative reform ineffective.

Accordingly, we engage with literature on epistemic injustice (Fricker 2007, 2017; Merrick 2019; Carpenter 2018, 2023; Carpenter and Jordens 2022; Ziemińska 2020; Griffiths

2023) reflecting on the interaction between law, cultural invisibility and epistemic injustice. In this sense, we evaluate GIGESCA's ability to address two key forms of intersex epistemic injustice: testimonial injustice, where intersex voices are discredited as a result of their lived experience (Carpenter 2018); and hermeneutical injustice, where intersex people are "unable to make sense of their experience due to prevailing social norms." (Carpenter 2018, p. 459; Ziemińska 2020, p. 54). Invisibility arises from (and also contributes to) a lack of shared social resources for intersex or endosex people<sup>2</sup> to understand intersex lived experience. The result is further marginalisation which "perpetuates the lack of resources needed to understand those experiences" (Goldberg 2020, p. 37). We ask, how far has law reform in Malta been able to remedy such injustice and what can we learn from this experience?

Chiefly, although there has been some political recognition of intersex by policy-makers and through legislation, this article provides new evidence that a cultural silence remains around intersex bodies despite legislative reform. While GIGESCA attempts to redress testimonial injustice, there is nothing in GIGESCA or surrounding policy discussions and initiatives that specifically addresses hermeneutical injustice and may even contribute to it. Consequently, gains in political visibility have not been made elsewhere. Our respondents felt that the legislation had very little effect on cultural understandings and familiarity with intersex issues. Problems such as stigma and shame as well as conflation with trans concerns further encourage the epistemic silencing of intersex issues. Moreover, medical professionals continue to be limited by epistemic injustice and the difficulties that presents for intersex people and their parents who are navigating healthcare spaces. A hermeneutic justice gap thus remains which fundamentally hinders the efficacy of law reform in Malta, with evidence showing that people may not even realise that the rights available through GIGESCA apply to them. Unless the cycle of cultural invisibility is broken, legal reform may be rendered ineffective. While the law's ability to challenge epistemic injustice in Malta may be attributable to Malta's distinct cultural, political and medical context, there are some more general lessons to be learned from Malta's experience. Notably, states who wish to improve intersex lived experience must combine top-down initiatives such as introducing legislation with alternative mechanisms of regulation and education.

The article now outlines GIGESCA before turning to an overview of epistemic injustice specific to intersex people. We then set out the methodology used for our empirical project before setting out our findings relating to three categories of visibility: political visibility, cultural visibility and medical visibility. We then finally consider how to improve intersex visibility within and outside of Malta and ways in which we might overcome hermeneutical injustice in this arena.

# 2. An Overview of The Gender Identity Gender Expression and Sex Characteristics Act 2015

GIGESCA arose as a response to a legal case which centred on a trans womans' right to marry.<sup>3</sup> The case was intended to go to ECHR, but settlement was reached between Malta and the claimant whereby Malta promised to introduce a swathe of progressive LGBT reforms including a gender recognition act, now GIGESCA.<sup>4</sup> Although the outgoing Nationalist Party government recognised the need for legal reform to protect the rights of gender-diverse people, these were ultimately driven by a newly appointed Labour Government. However, GIGESCA was not initially designed to include intersex-specific provisions (Garland and Travis 2023). Rather, lobbying for the introduction of a Gender Identity Bill in Malta started in 2010 (Falzon 2010) but its first iteration was only addressed towards trans people. The first draft referred to the establishment of a 'Transgender Persons Register' which would be accompanied by a "procedure for the recognition of a person's gender." Policy-level engagement with international intersex organisations placed the need for legal reform on the agenda (Garland and Travis 2023). Significantly, the Third International Intersex Forum was held in Malta in 2013 with good engagement from policy-makers and led to the intersex provisions being added to the Bill by the time that it was first read in

Parliament in October 2014. The first draft of the Bill underwent a public consultation, and numerous organisations and institutions, both local and international, submitted their comments (Falzon 2010, p. 40). These submissions—unsurprisingly—emphasised the lack of cultural visibility as most made no reference to the intersex provisions and the few that did were either from international intersex organisations or were particularly concerned that the public still did not know the differences between intersex and trans. Accordingly, the introduction of the intersex provisions within GIGESCA appeared to happen with little notice or attention from the public in Malta (Garland and Travis 2023) with the focus instead being held by debates around trans rights.

Despite the lack of attention, the provisions that were introduced were significant. Alongside equality laws that protect intersex people from discrimination and hate crimes, GIGESCA was the first piece of legislation which included a prohibition on non-consensual non-therapeutic surgeries prohibited "until the person to be treated can provide informed consent.' (s. 14(1)). The act also included criminal penalties for those that breached this prohibition<sup>6</sup> and instigated a raft of changes to healthcare provision for intersex people. GIGESCA also sought to improve intersex healthcare experiences. Under ss.14(4) and 14(5), GIGESCA also sought to establish an interdisciplinary team (IDT) charged with overseeing healthcare provision for intersex children. Treatment could only be carried out if an agreement was reached between the parents and the interdisciplinary team. This provision appears to give equal authority to the parents and the group of experts; however, the Act does not address the possibility of an impasse or provide possible solutions for any disagreements between the parents themselves, or between the parents and the IDT. GIGESCA aspirationally introduced s.15(1) which states that individuals "seeking psychosocial counselling, support, and medical interventions relating to sex and gender should be given expert sensitive and individually tailored support..." and this support "should extend from the date of diagnosis or self-referral for as long as necessary." While not specifically addressed at intersex people, this section was also a step in the right direction. As opposed to the previous section, s.15 does not appear to address minors but rather any persons, whatever their age, should be able to seek psychosocial care when and for as long as they need it.

The sentiment of the intersex provisions in GIGESCA was certainly a positive one and was welcomed by intersex activists around the world (Garland and Travis 2018). Yet the Act itself was never intended to address the issue of intersex invisibility. Rather it was intended to grant specific rights and obligations to intersex people and medical practitioners. However, given that Fricker (2007, p. 154) states that silence within healthcare itself means that "the whole engine of collective social meaning [is] effectively geared to keeping [intersex experiences] out of sight", GIGESCA's focus on illuminating and changing medical protocols marks a potential shift towards greater cultural visibility. This article explores whether greater cultural visibility has followed GIGESCA. Understanding this, as the next section demonstrates, is crucial to understanding the efficacy of the legislation. If intersex remains culturally invisible outside of the legislative context, affected individuals will simply not know that rights and obligations will apply to them. Thus, the law's utility and the value of legislation will be limited.

# 3. Intersex People and Epistemic Injustice: The Need for State Action

In recent years, there has been increasing engagement with the notion of 'epistemic injustice'. Starting with Fricker, epistemic injustice has been characterised as a set of circumstances whereby an individual is "ingenuously downgraded and/or disadvantaged in respect of their status as an epistemic subject" (Fricker 2007, p. 53). Ballakrishnen and Lawsky further this by describing it as "refus[ing] to accept someone as a person who is capable of knowing things and of communicating that knowledge is to dehumanize them" (Ballakrishnen and Lawsky 2022, p. 1031). According to Fricker (2007), epistemic injustice includes both testimonial and hermeneutical injustice. The former refers to situations whereby the testimony of that person is devalued on account of an aspect of their identity

Soc. Sci. **2024**, 13, 150 4 of 20

(Merrick 2019, p. 4433; Fricker 2007, p. 29). For example, intersex people's accounts of medical harms are often discredited owing to structural identityprejudice which depicts intersex people as 'less rational' or 'untrustworthy', particularly in comparison to medical practitioners who use this prejudice to refute such accusations of harm (Merrick 2019, p. 4433; Fricker 2007, p. 29). Indeed, Merrick explains that victims of testimonial injustice are often members of groups typically "barred from fully participating in the institutions tasked with generating the culturally dominant hermeneutical resources" (Merrick 2019, p. 4433). In the context of intersex people, there has been a historic exclusion of intersex voice both in "determining and evaluating medical care" (Merrick 2019, p. 4435), and the inappropriate pathologisation of intersex people demonstrates evidence of such testimonial injustice (Luzzi 2021, p. 4; Merrick 2019; Davis 2015). In this sense, then, the introduction of GIGESCA, legislation that has been actively designed to respond to the concerns of medical harm raised by the intersex community in the International Intersex Forum in 2013 in Malta, marks a state-led initiative to respond to testimonial epistemic injustice. This article considers whether GIGESCA has successfully redressed intersex testimonial injustice.

Moreover, epistemic injustice also arises in contexts where "a gap in collective interpretative resources puts someone at an unfair disadvantage when it comes to making sense of their social experience" (Fricker 2007, p. 1). This has been characterised as 'hermeneutical injustice' (Fricker 2007, p. 1). As Ziemińska explains, "hermeneutical injustice is a structural notion, and no agent perpetuates the injustice (even unintentionally). It is a structural vice of the social imagination" (Ziemińska 2020, p. 53), and, as Carpenter notes, it arises in situations where individuals have "no access to concepts and terms that can describe their experience" (Carpenter 2023, p. 4). Thus, in the context of GIGESCA, hermeneutical injustice can mean that *accessing* available rights in the law is not possible.

The concept of epistemic injustice has increasingly been used in relation to intersex people (Carpenter 2018, 2023; Carpenter and Jordens 2022; Ziemińska 2020; Griffiths 2023). General familiarity with the term intersex is low (Hegarty et al. 2021). The lack of epistemic and cultural knowledge about intersex people arises from a societal enforcement of the gender binary (Dreger 1998; Ziemińska 2020; Foucault 1980) and a medical establishment that has historically focused on secrecy around intersex variations (Hegarty and Chase 2000; Davis 2015; Carpenter 2023). As Carpenter notes:

Non-disclosure or motivated disclosure of a diagnosis, and use of language that disconnects individuals from peer support, are widespread phenomena that leave individuals with significant gaps in understanding about their bodies and an inability to connect with others. These forms of disclosure mean that the authority of biomedical professionals is boosted, while the voices of community and parents are systematically marginalised in ways that limit agency and participation in decision-making. (Carpenter 2023, p. 15)

This article asks, then, whether in Malta, GIGESCA has been able to remedy this form of epistemic injustice and increase cultural visibility. Medical professionals and guidelines have been instrumental in denying intersex peoples' knowledge of their own variations and bodies and, in many ways, hindered the establishment of intersex communities, which can make it difficult for individuals to mobilise. Since at least 2006, professional medical guidance has rowed back from its position of secrecy towards dialogue with parents and intersex children. Nonetheless, healthcare's change in nomenclature from 'intersex' to 'DSD' (Disorders of Sex Development) has been seen by some as an intention to "wrest epistemic authority back from the nascent intersex movement" (Carpenter 2023, p. 8; Davis 2015) and as re-entrenching "clinical power to delineate and silence those marked by the diagnosis" (Holmes 2011).<sup>8</sup>

At the same time, since the early 1990s, intersex activists have worked with LGBT activists to create visibility and community space (Preves 2003). This has created a nascent but contrasting epistemology of intersex whereby it is characterised through the lenses of LGBT and increasingly non-binary embodiment (Garland and Travis 2023). As Griffiths explains, "Historically, there have been two dominant frameworks within which intersex

Soc. Sci. **2024**, 13, 150 5 of 20

has been made intelligible or recognizable: that of biomedicine, and that of gender and/or sexuality" (Griffiths 2023, p. 13). As Carpenter highlights, "The resulting hermeneutical injustices have material effects where, for example, the use of 'disorders of sex development' terminology in clinical settings, and the term 'intersex' in community, human rights and LGBTQ spaces has sometimes led to the construction of incommensurate and contradictory policy frameworks, as if referring to distinct populations" (Carpenter 2023, p. 6; see also Garland and Travis 2023). Framing intersex experiences through a singular framework can thus create its own form of "epistemic violence, whereby intersex demands, testimonies and politics are ignored in favour of more dominant narrative" (Griffiths 2023, p. 13).

Consequently, Ziemińska highlights that the cultural visibility of intersex people is "a structural problem" (Ziemińska 2020, p. 54), that we are "prisoners of the social imagination that is created by the whole society" (Ziemińska 2020, p. 60) and that intersex "voices cannot be understood in the public arena" (Ziemińska 2020, p. 54). To remedy this, Fricker suggests the need for more empirical data and to prioritise the voices of minority groups (Fricker 2007, p. 162), suggestions that are bolstered by interdisciplinary intersex studies (Monro et al. 2021) and that we seek to add to in our recommendations from this study.

The need for participation and voice echoes work that has been done in the spheres of equality and social justice. Sandra Fredman, for example, has made enhancing voice and participation one of the core tenets of her multi-dimensional approach to substantive equality, alongside the related notions of addressing stigma, stereotyping, prejudice and violence, and accommodating difference and achieving structural change (Fredman 2016, p. 713). Political visibility is thus a priority in redressing epistemic injustice. This is not only addressed through legislation but through ongoing opportunities to create meaningful dialogue between intersex people and the state. As Merrick (2019) states, combatting testimonial and hermeneutical injustice requires both societal and institutional remedies to neutralise prejudice against intersex people and "policy setting bodies must also cultivate this and correct for adverse dialogical effects due to hermeneutical marginalization" (Merrick 2019, p. 4434). Moreover, it may involve funding peer-support networks for intersex people to develop their own sense of community (Garland and Travis 2018).

Accordingly, for GIGESCA to mark a watershed moment in terms of legal rights, there must be an accompanying shift in epistemic injustice to ensure the possibility of participation. Unless individuals can articulate harms and access rights, legal reform is in danger of being a superficial response to the problematic medical responses in this area. We now turn to the results of our empirical project to examine whether the reform in Malta was accompanied by (or indeed led to) a change in epistemic and cultural knowledge about intersex.

# 4. Materials and Methods

This research was funded by the British Academy and sought to examine the impact of GIGESCA's intersex provisions on the Maltese intersex population. To do so, the authors conducted a systematic literature review of the following: relevant laws in place before and after GIGESCA was introduced; transcripts of parliamentary sittings during which the Bill was being discussed; newspaper articles, both local and international; and other local and international reports. Beyond this, the primary aim of our research was to analyse the social impact of this specific legal reform; a series of semi-structured interviews with a diverse cohort of stakeholders was planned. This exercise established the personal and social contexts that surrounded GIGESCA and allowed for deeper exploration of its aims and the impact of the changes that it introduced.

Requests for ethical review were successfully submitted to the University of Malta and the Maltese Health Ethics Committee. Since the intention was to interview Maltese nationals, documentation in both the Maltese and English languages was prepared. Notably, most Maltese nationals are bilingual, however it was felt that giving the option of replying in either language would enable respondents to choose the language they preferred. As

Soc. Sci. **2024**, 13, 150 6 of 20

one of the researchers is Maltese and can speak the language fluently, it was possible to offer the option of holding interviews in Maltese.

Recruitment was mainly done through an open invitation. Invitations were sent to professional associations and entities for distribution among their members. In some instances, respondents themselves recommended that invitations be sent to other individuals with experience in the area. Eleven professionals—two lawyers, three policy-makers; two involved in advocacy work, and four healthcare professionals (nursing, paediatric surgery, psychology and endocrinology)—sat for a semi-structured interview carried out over Zoom between 2022 and 2023. The transcripts were anonymized, and thematic analysis was carried out. Owing to Malta's population size, additional difficulties exist relating to anonymization, as it potentially means that there is more identifiable information which will need removal during the anonymisation process. To mitigate this, we not only anonymised respondents' details such as their name, but followed processes for small populations recommended by Saunders et al. (2015).9 Data were analysed thematically (Braune and Clarke 2015), with themes generated around issues relating to cultural knowledge, visibility and epistemic injustice. Whilst the views of our respondents differed on a number of important topics, in relation to epistemic injustice and evaluating whether Malta had been a success in those terms, they were in consensus.

Unfortunately, no intersex persons or parents of intersex children accepted the invitation to be interviewed. Although the professionals' perspectives proved to be insightful, failure to obtain the intersex persons' experience is considered a major limitation of the study. In part, the reasons for this lack of recruitment may be explained through the discussion of epistemic injustice that we now turn to in this article. For example, some of our respondents held the opinion that many intersex people may not even realise that they are intersex or that this research was addressed to them. In Sections 5.2.2 and 5.2.3, we reflect on issues of stigma and lack of self-knowledge and their links to hermeneutical injustice within intersex experiences in more detail. This, coupled with the idea that stigma was perceived to be increased in Malta may have affected our ability to recruit. What this does mean, however, is that our conclusions are without reference to intersex people in Malta and thus are limited in terms of what we can learn. More research is needed, and careful thought as to how to engage participants must be given by researchers in the context of the hermeneutical injustice experienced by intersex people.

We now present our findings with regards to three themes: political visibility, cultural visibility and visibility in healthcare.

## 5. Results and Discussion

### 5.1. Theme 1: Political Visibility

Despite its track record for its Catholic conservativism and its historically restrictive approaches towards abortion and divorce, Malta introduced a swathe of progressive LGBT rights in the 2010s, making it one of the most progressive states in Europe in this regard. Notably, GIGESCA was a huge change in legislative engagement with intersex issues, not just within Malta, but globally (Garland and Travis 2018, 2023; Ní Mhuirthile 2018). The legislation was comprehensive and forward-thinking—seeking to both protect intersex people but also ensure access to support from healthcare professionals over the life course. The design of GIGESCA clearly benefitted from the participation and voices of intersex people. Several of our respondents noted the participation of Government Ministers at the Third International Intersex Forum held in Malta in 2013.

...the minister had the opportunity to meet a number of intersex activists from around the world when they had I think it was the second or the third international intersex forum that ILGA Europe was conducting in Malta. So the minister had this opportunity, you know, to listen to the stories of so many people and I think, from what I know, she felt compelled that she needs to do something about this. ... think it was a big chance, a bit you know, pushing by the right people at the right time. (Respondent 4—advocacy)

Soc. Sci. **2024**, 13, 150 7 of 20

Malta's ability to introduce such progressive rights was attributed by our respondents to several individuals within the government having familiarity with intersex issues through their work with international LGBTI organisations.

...the Minister at the time was surrounded by two people who have done a lot of work around intersex persons globally. (Respondent 4—advocacy)

...within the ministry at the time [there were] two people who had been chairing the International Intersex Forums on behalf of ILGA-Europe and ILGA, who therefore knew more and could drive that process. (Respondent 2—policymaker)

Our respondents were keen to highlight, therefore, the fortuitous set of circumstances that led to intersex issues being included within the scope of GIGESCA. Here, the participation of individual actors and the Ministers' access to the testimonies of a range of international actors made a huge difference to the government's epistemic unfamiliarity with, understanding of, and commitment to these issues. Whilst Malta did not have a wide-reaching intersex-led NGO, the existence of these key actors and moments were crucial to driving forwards social change.

...in reality, intersex issues were relatively new to the movement at the time and so were not necessarily being pushed by the civil society organisations. But when the law was proposed, or rather, when political will was expressed in terms of passing the GIGESC Act from the political side, it was always intended to include intersex issues. So in this sense, that part of the law was more government- than society-led and mainly because there was not a lot of knowledge I would say of civil society on intersex issues. (Respondent 2—policymaker)

At this level, then, the political climate within Malta was able to counter the testimonial injustice-induced credibility deficit that often pervades political and institutional responses to intersex experiences. Indeed, tribute to such political awareness can be found in GIGESCA's attempt to redress some testimonial injustice within the scope of the Act. The drafting of GIGESCA's intersex provisions used deliberate language to ensure that the Act's remit was wide, casting the right to be free from unnecessary physical interference without the express consent of the individual under s.14 broadly. Significantly, the legislation does not actually use or define the term 'intersex' but instead it prohibits "any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention" rather than interventions on intersex minors. Section 2 further defines 'sex characteristics' as:

the chromosomal, gonadal and anatomical features of a person, which include primary characteristics such as reproductive organs and genitalia and, or in chromosomal structures and hormones; and secondary characteristics such as muscle mass, hair distribution, breasts and, or structure.

The legislature's choice to use 'sex characteristics' instead of 'intersex' was intended to make the application of this legal right wide-reaching and avoid reliance on the medical institution to provide a diagnosis before an individual can invoke s.14, removing some of the barriers that perpetuate testimonial injustice. Legislators specifically wanted to avoid medical 'gatekeeping' of these rights by allowing them to determine whether an individual is or is not 'intersex' for the purposes of GIGESCA's protective provisions. As one respondent stated:

[policy-makers] wanted to make sure that minors would be protected even when they are not diagnosed as intersex because of course . . . there is a lack of awareness on what being intersex means and that includes the medical community. So if you have a minor that is not correctly diagnosed but is still recommended for surgical interventions on their sexual organs so on and so forth, they are still protected by this law. And that is what [policy-makers] wanted to do. So [they] did not want a law to be restricted to apply only when there is a DSD diagnosis. (Respondent 5—Law)

In addition to this, the working group which was set up to review and develop the medical protocol regulating intersex care per s16(6) was to consist of an equal mix of human rights experts, psychosocial practitioners, and medical professionals. The inclusion of human rights professionals was specifically to ensure that the experiences of intersex individuals in terms of medical harm were taken seriously by the working group so that a model of best practice could be developed:

... an interdisciplinary panel that establishes treatment protocols ... should try to look at issues beyond the beyond the medical. So, trying to have protocols that look at social issues, look at self-determination issues as well, issues which, as we mentioned before, medical practitioners might not be too ready to think about, or even accept immediately. So, to really bring in more than the just medical into the conversation. (Respondent 11—Law)

While GIGESCA does not contain reference to the inclusion of patient groups or intersex individuals, it is a significant attempt to remedy testimonial injustice experienced by intersex people in relation to discussions about appropriate medical care. Indeed, the very nature of the intersex provisions is to redesign the provision of healthcare in a way that responds to intersex experiences, acknowledging that surgeries on infants amount to criminal harms.

However, post-implementation, this has not redressed testimonial injustice. In fact, there has been a huge delay in GIGESCA's implementation due to a lack of definitional and terminological consensus between human rights experts and medical experts. As a result, the protocol has not been finalized, and thus, the full remit of the act is not yet set. This schism between human rights narratives and medical narratives over intersex is well documented (see e.g., Carpenter 2018; Garland and Travis 2020a). In Malta, this divide is a pervasive issue relating to epistemic injustice, where healthcare practitioners often appear impervious to, or even dismissive of, claims of human rights violations in this arena from supranational bodies such as the UN and the European Court of Human Rights (Garland et al. 2022). In Malta, this debate has really centered on whether hypospadias should or should not be included within the definition of 'intersex'.

... they're still discussing ... the basic concept of the word intersex, because the way [medical professionals] see this category of people is, you know, this is a condition, a disorder of sex characteristics, and we're talking a very different language. And others are saying no it's not a disorder, but it's a difference, or it's a diversity. And they're [medical practitioners] thinking of, you know, what is the standard or kind of the golden standard of what a vagina and what a penis should look like, and what other intersex conditions should be considered as intersex conditions include the hypospadias, for example. (Respondent 2—policymaker)

Accordingly, testimonial injustice pervades in the aftermath of legislative reform. It supports Merrick's assertion that "...the prevailing perspective or practical identity of a Western healthcare professional is not entirely well-suited for virtuously listening to patients or their non-medical advocates" (Merrick 2019, p. 4445). Accordingly, both Merrick and Fricker argue that to cultivate institutional testimonial justice, or what Merrick defines as being biomedical testimonial injustice, there must be greater "respect for a patient's epistemic agency and interpretive competence part of the practical identities of healthcare practitioners and providers" (Merrick 2019, p. 4445). Yet, there has not been the political capacity for this in Malta. While there has been some commendable political visibility, post-GIGESCA, it has been difficult to create the climate necessary to remove the prejudice attached to intersex narratives. Indeed, politically, several changes since GIGESCA's introduction in 2015 have diluted the efficacy of political visibility. As respondent 3 (advocacy) highlights:

Keep in mind that we've had a lot of political changes over the past few years in Malta, and every time there is a change in Minister, then any Ministry-appointed boards have to resign. It's a courtesy. They call it a courtesy but you have to resign in case the minister

happens not to like you and doesn't want you on the board. The new minister, right. And [Malta's] had a few of those, you know, changes, over the past years we've had ministerial changes. That obviously doesn't help because everything is at a standstill until the new minister is in place and says yes ok, the board can continue at it was, or whatever.

Political instability has, therefore, also contributed to the delays faced by the Working Group and, thus, the full implementation of GIGESCA. In the next section, we outline some of the issues around cultural visibility and how epistemic injustices have hindered the implementation of GIGESCA. In the absence of a strong alternative, it is perhaps not surprising that the medical profession has been able to continue to shape the epistemic direction of implementation.

Moreover, as discussed below, whilst political visibility was hugely successful in terms of introducing legislation, its attempt to address testimonial injustice may have actually exacerbated hermeneutical injustice through the absence of a clear relatable term such as intersex or even specific variations. This lack of language consensus contributes to hermeneutical injustice through a persistent misalignment between social, political and medical understandings of intersex. Without terminological consensus, medical framings of 'disorder' continue to dominate understandings of what intersex is. This dominant framing constructs intersex through a particular lens and, in many ways, prevents its mobilisation as an ontological category. Our argument here is not to suggest that any particular term is more or less preferrable—indeed, there is plenty of evidence to suggest that the avoidance of labels helps avoid inappropriate pathologisation and recognises the multiple experiences of individuals with intersex variations, many of whom do not wish to, nor realise that they may, come under the umbrella term 'intersex' (Topp 2013; Viloria 2017; Malatino 2019). However, as noted below, in the absence of clear cultural knowledge and understanding, a lack of clarity over just who may be protected by s.14 has not only led to stalling by the medical profession post-implementation, and a potential co-opting of this legislative space, but individuals may simply not realise that the Act is intended to protect them. The rights contained within the Act are rendered unintelligible because there is a lack of language for people who need or wish to apply it. Indeed, as part of the consultation process for GIGESCA, Organisation Intersex International Australia (now the Intersex Human Rights Australia IHRA) submitted a consultation response which suggested that "the proposed language around 'sex characteristics' would benefit from either the additional inclusion of a legal definition of 'intersex', or mention of 'people with intersex variations' to "promote legal and societal clarity about the full diversity of sex characteristics of people that arise in nature."11 Some of our respondents also recognised that better oversight of definitions was needed or would have helped particularly around the inclusion of hypospadias.

This, combined with no visible third sector organisation pushing for this reform, means that much of the legislation around intersex seems to have gone unnoticed by the broader public including both endosex and intersex people allowing hermeneutical injustice to perpetuate. Thus, the implementation stages of GIGESCA have been affected in part due to a lack of intersex stakeholders capable of providing their voices to ensure the accountability and transparency of governance in this area.

# 5.2. Theme 2. Cultural (In) Visibility

Unlike political visibility, our focus on cultural visibility refers to the wider public awareness of intersex at the individual and interpersonal levels. In this sense, we analyse the discursive awareness of intersex and how far it still remains unintelligible within wider society (Butler 1990). While we are unable to draw from intersex voices, our respondents nevertheless provided insight into the hermeneutical progress made in this arena. Respondents reflected on how far these legal reforms had been able to infiltrate wider societal (and in Section 5.3 healthcare) discourse and remedy hermeneutical injustice.

# 5.2.1. Cultural Invisibility

Despite the growing political recognition of intersex and its effect on legislation, our respondents suggest that this was yet to translate to a general hermeneutical cultural awareness of intersex embodiment and its related issues. In keeping with general low levels of cultural awareness of intersex variations (Hegarty et al. 2021), respondent 10 (healthcare) stated that:

If you speak to lay persons and ask what do you know about intersex, what do you know about the intersex condition, or persons who have been diagnosed as intersex? No idea!

One aspect of the limited visibility of intersex people was attributed to a lack of visible role models and community leaders. As respondent 4 (advocacy) notes:

Well, first of all, I think the lack of awareness and visibility is something that is still very much present, and... you know we're educating people out there about intersex conditions. But there isn't anyone visibly Maltese appearing on media and talking about their experience, unlike all of the other identities within the LGBTIQ community. So, I think that makes it quite difficult for other intersex persons to reach out, to be part of the Community and to have Community support.

This is perhaps unsurprising, given that Malta is a small conservative Catholic jurisdiction which, as we discuss below, exaggerates the difficulties in speaking openly about being intersex. Yet, visible role models are an important aspect of recognising a community not just for the wider culture but, as will be discussed in the next section, for self-recognition. Not only were intersex people themselves not visible, but there was limited hermeneutic awareness of what intersex is. This supports the view that the issues that intersex people face are hermeneutically epistemic (Carpenter 2018, 2023; Carpenter and Jordens 2022; Ziemińska 2020; Griffiths 2023). Without the vocabulary and conceptual scaffolding to place intersex within the cultural schema, legislative change has been unable to increase cultural visibility. As respondent 5 (Law) explains:

Not many people pay a lot of attention to what's happening in Parliament. So, I would not be surprised that at the time they were not aware. Now I am hoping things changed, you know, 7 years after that. . . . I believe it was a case of law driving society forward and not vice versa. Sometimes you get society pushing for legal change. In this case I think it was very top-down approach, which is good in a sense because it needed to happen and it needed to happen fast, but at the same time you'd get this disconnect.

Respondent 5 (Law) highlights that the pressing need for GIGESCA and its perceived time sensitivity meant that the legislation was largely dictated by a core group of 'experts' rather than stemming from a broader social movement. The speed with which intersex was included into GIGESCA and the political strategy around it meant that there was limited consciousness raising attached to intersex at the time of the Bill's passing contributing to the lack of attention paid to the need to remedy hermeneutical injustices. The lack of a social movement pushing for this legislation can also be explained through hermeneutical injustice, as discussed in the next section.

#### 5.2.2. A Lack of Personal Awareness

Our respondents felt that intersex people within Malta would not have the conceptual or cultural resources to understand that they were intersex. This issue of hermeneutical injustice helps to potentially explain the difficulties in recruiting intersex people in this study. As respondent 1 explains, "I wouldn't be surprised if there were people out there who just didn't know they were intersex. Didn't know this [law] was meant for them." Our respondents felt that the cultural conditions within Malta (of conservativism, Catholicism, medical stigma) meant that it would be unlikely for intersex people to have the imaginative tools necessary to identify with intersex labels—a core tenant of hermeneutical injustice. As respondent 10 (healthcare) explains:

Also being a very small area geographically, and also being, from the social aspect, people are very much related and also go around everyday activities very much within the same people, you see, it's still a secret. It's a very secretive kind of thing. I think it's very much related, as well, to the erroneous idea of the Catholic culture being predominant in Malta.

This secretive approach would go some way to explaining our difficulties with recruiting intersex Maltese people (and parents) to our study. It would similarly explain the very small minority of intersex people on the 'Working Group' set up as part of GIGESCA to oversee the creation of healthcare protocols related to intersex people informed by both healthcare and human rights approaches.

This hermeneutical injustice has material effects when considered in the context of GIGESCA. The 'success' of the legislation is dependent on its use. Whilst this may, for the most part be measured in terms of its deterrent effect on medical professionals it also presupposes the idea that its constituent population is aware enough of the legislation to utilise it. Our respondents felt that this was not the case:

What I can tell you . . . is that most of our clients know nothing of it [GIGESCA] . . . (Respondent 10—healthcare)

Nothing. Zero ... there haven't been any legal queries from any intersex person. Nothing. I mean, when you have all the conditions in place for a person to enjoy rights, speak to NGOs for advice and support, you know, and everything is in place favouring the situation, and there's still a lack of engagement, then ... it goes to show how invisible, how disenfranchised, how disempowered, how afraid people are. (Respondent 11—Law)

This is an important point, without the cultural awareness to use it, GIGESCA is, at least for intersex people, futile, particularly in a context whereby doctors claim the legislation does not apply to them. Moreover, the lack of visible intersex people creates broader problems—without community input, it is difficult to monitor the 'success' of this legislation or to consider whether different forms of interventions are necessary. Indeed, this research study and others indicates the difficult of recruiting much needed intersex voices. As respondent 3 (advocacy) highlights: "The largest one, for me, not necessarily for them, is complete invisibility. They are completely invisible. And if they're invisible, then we don't really know what their issues are. And we can't do anything, you know, to deal with whatever their issues are". The difficulties with visibility lead directly to a lack of participation and voice, which, in turn, prevents support for intersex people being led by their own desires and needs—hermeneutic justice becomes embedded and self-perpetuating.

Similarly, without self-recognition, it is difficult to build a wider network of community support. The hermeneutical injustices present in Malta (and elsewhere) have hindered the development of a visible and active intersex movement. This, for some of our respondents, was compounded by feelings of shame and stigma associated with intersex variations and is likely exacerbated by the lack of reference to intersex in the legislation.

# 5.2.3. Stigma/Shame

Our respondents felt that the lack of personal awareness of intersex variations was intensified by issues of shame and stigma within Maltese society. These feelings of shame led to parents deliberately withholding important facts about children's medical histories from them.

... we don't tell the kids themselves who have a right to information about themselves, we don't tell the relatives—God forbid we tell the relatives! Therefore, this whole thing becomes a shameful secret still. (Respondent 10—healthcare)

... there is an element of shame in the parents for having failed to produce a 'perfect' boy or a 'perfect' girl, then being referred. (Respondent 3—advocacy)

These reports are in keeping with general observations of parent's treatment of intersex variations—particularly prior to the 2006 Consensus Statement (see for example Hegarty and Chase 2000) and reflect the high rates of decisional regret that parents feel in these

circumstances (Roen et al. 2023). Some respondents pointed towards the word 'sex' in both intersex and disorders of sex development as a source of shame for conservative and Catholic parents that stopped them from fully engaging with resources available on their child's variation. The conceptual resources needed to combat hermeneutical injustice is thus stymied by cultural stigma and secrecy.

However, one respondent returned to themes of hermeneutical injustice, stating that, "I would say there is a stigma but I don't think I can even say that because it's so unknown, even as a possibility, that I won't even say there's a stigma attached to it". The lack of awareness around intersex, for this respondent, prevented its being understood through a lens of stigma, or perhaps it might be better understood as a stigma for which those that experience it lack the epistemic knowledge to articulate. Here, we reflect on our own experiences with this project: the experience of stigma, shame and fear of being 'outed' may have further prevented people from participating in the research. Malta is a small conservative island community where anonymity is far more difficult to maintain. <sup>13</sup> The perceived risk of being 'outed' as intersex may have outweighed the research goals for potential participants.

#### 5.2.4. Conflation of Trans and Intersex

Whilst our respondents felt that there was a cultural conceptual lack of awareness about intersex people, they felt that often this gap in knowledge was conflated with trans issues. This element of hermeneutical injustice was brought particularly to the fore in Malta, as GIGESCA predominantly dealt with trans issues and was, in many ways, a response to an ECHR case (that had been settled before a decision was made) that centered on trans people's access to marriage (*Cassar v Malta* 36982/11, see also Garland and Travis 2023). As respondent 5 (Law) notes:

And in particular with Malta, the hype with this law was not about the intersex provisions, so when it was enacted in 2014, the hype was mainly around the transgender community. The intersex provisions were rarely mentioned in the press, or when politicians spoke about it. It was very, very rarely heard of. So that's another issue in itself. . . .

In some ways, this reflected the strategy of the politicians supporting the Bill. Whilst there was opposition to components related to trans equality, very little attention was paid to the intersex aspects of the provisions (Garland and Travis 2023). As a result, at least for intersex people, the Bill was able to sail under the radar. Whilst this was useful for ensuring that the Bill passed into legislation, it may have had the negative effect of diminishing the cultural visibility of it, of the need for such legislation, and of intersex people in general, inadvertently perpetuating epistemic injustice.

Moreover, the inclusion of intersex within GIGESCA may have led to some conceptual or schematic conflation between trans and intersex issues. As one respondent (policymaker) highlights, "The issue is when it goes to the general public, I think. So perhaps the communication should make an explicit effort to distinguish the two issues". Unfortunately, this conceptual confusion is not uncommon (Griffiths 2023; Garland and Travis 2020b) and can lead to tensions between the trans and intersex communities.

Whilst the lack of public awareness around intersex is clear, the legislation was designed to foster cultural awareness within the medical profession. In the next section, we outline some of the difficulties that have been encountered in that space.

# 5.3. Theme 3. Visibility within Healthcare

Whilst there was some recognition of and knowledge pertaining to intersex issues at the political level, our respondents suggested that this, thus far, seemingly failed to transfer across to wider society within Malta. Our research also explored, however, how far healthcare professionals perpetuated or were themselves bound by epistemic injustice. Understanding this is key to this project, given that healthcare is the one institution that intersex individuals, particularly in infancy, and their family will encounter to discuss care. Even though several medical professionals were invited to participate in this research, many of those contacted stated that they could not take part, as they knew nothing about

intersex, highlighting continuing levels of hermeneutical injustice in the very community the legislation was designed to target. This is confirmed by some of the respondents:

... not even healthcare professionals like nurses for example were aware that these people even exist. We don't see them much, somehow. (Respondent 8—healthcare)

The fact that no medical protocol, no Interdisciplinary Team, and no specific Intersex Wellbeing Clinic have yet been set up, further perpetuates the invisibility of intersex people within the healthcare system and reinforces hermeneutical injustice. Those who were diagnosed in the past also seem to have been lost within the system, with no follow-ups and no long-term care.

Again, it's difficult in a sense to justify both sides of the coin when we know so little in terms of outcomes, when we cannot trace the impact that certain interventions have had on intersex people because they are completely invisible. This has been an issue ... (Respondent 2—policymaker)

Hermeneutical injustice thus also exacerbates poor healthcare practice for intersex people. The lack of follow-up care reinforces the idea that many intersex people in Malta may be unaware of their variation, or may not conceptualise it in terms of intersex. Again, this limits the effectiveness of GIGESCA, as people will be unaware that it applies to them. Lack of knowledge amongst healthcare professionals allows and enables the further marginalisation of intersex people by promulgating stigma and shame. Drawing on Fricker (2007, p. 154) as we noted above, silence within healthcare itself means that "the whole engine of collective social meaning [is] effectively geared to keeping [intersex experiences] out of sight". While investigating the impact GIGESCA had on knowledge about intersex within healthcare so far, we identified issues relating to medical terminology and medical awareness of law and legal obligations.

### 5.3.1. Medical Terminology

Indubitably, the language used by medical professionals can affect the way intersex people perceive themselves and how they are perceived by others. Terminology can create 'framing effects' that can prevent people from understanding their experiences in particular ways (Streuli et al. 2013; Garland and Travis 2023; Carpenter 2018; Davis 2015). Framing intersex as a disorder which can be 'fixed' by medical intervention prevents parents and intersex people from accessing the conceptual tools needed to think otherwise and is a strong driver of hermeneutical injustice. The use of 'disorders of sex development' (DSD) therefore, whilst not unusual in the healthcare sector, illustrates another method through which hermeneutical injustice is perpetuated and continues the cultural invisibility of intersex people.

Interviewer: . . . the word intersex, is that ever used in the clinical setting?

Respondent 7 (healthcare): Not really.

Yet NGOs and third sector organisations who are committed to supporting the same people use the term 'intersex'. DSD or the specific variation diagnosed, such as CAH or CAIS, are the terms more commonly used in the clinical setting in keeping with the general findings of Lundberg et al. (2021). International medical norms predominantly dictated by the Chicago Consensus Statement (Lee et al. 2006) had been largely untroubled by the presence of GIGESCA and medical professionals had largely failed to consider how GIGESCA might challenge their definitions and practices.

Despite GIGESCA's potential for an epistemic shift, the language used in the health sector continued to be 'medicalized,' and included terms such as disorders, symptoms, and signs. More shockingly, and in comparison to the absence of the term 'intersex', the term 'hermaphrodite' was still used, even though it has been largely condemned by both the intersex community and international medical protocols.

... the word hermaphrodite is still used, for example. If you tell them hermaphrodite they might click, and say, ah, a hermaphrodite, ok, now I understand. But intersex is still something which is not known. (Respondent 8—healthcare)

...we're still discussing with a number of medical professionals even on the basic concept of the word intersex, because the way they see this category of people is, you know, this is a condition, a disorder of sex characteristics, and we're talking a very different language. (Respondent 4—advocacy)

GIGESCA has not led to a paradigm shift in how intersex is conceptualised in the Maltese healthcare professional, and so it continues, in many ways, to reinforce hermeneutical injustice by failing to give intersex people and their families the conceptual tools to articulate the issues that they face. Even where healthcare professionals are engaged in dialogue regarding the development of medical protocols, they have consistently demonstrated a reluctance or perhaps inability to consult with intersex people on the development of guidelines.

# 5.3.2. Medical Awareness of Law and Legal Obligations

Further to this, when asked about their knowledge of GIGESCA, many of the respondents admitted that they either did not know much about the legislation, or nothing at all.

Interviewer: So, the law that we're interested in, do you know anything about the law, or anything about the political discussions in Malta?

Respondent 7 (healthcare): *Um, not really.* . . . *I've got second-hand information that there were discussions with the LGBTQ movement regarding pushing to avoid doing surgery in these patients until they are at an age that they can give consent themselves. I'm not sure if this is anything to do with the Law or if it's something else that is still coming up.* 

There is a sense then that while many intersex people may not know GIGESCA applies to them, similarly where healthcare practitioners lack the language to discuss this phenomenon and understand how it relates to their work, they may also not realise that GIGESCA applies to them. This is a matter, then, of both protection and enforcement. There is yet no common understanding of what falls under the umbrella term 'intersex.'

No criteria that defines 'intersex'... evident that people, professionals, met people who are transgender but when it comes to intersex, people from (various clinics) recalled of meeting babies but only babies with ambiguous genitalia—that is what they understood by intersex. (Respondent 8—healthcare)

Within the medical setting, DSD also means different things for different people – compared to other medical diagnoses such as cleft palate, in which corrective surgery is advocated routinely.

Hypospadias (is) quite common in Malta. When it's severe, like scrotal or perianal, they should work up for ambiguous genitalia but instead, if testes are present, then it has to be a boy and proceed with hypospadias repair. (Respondent 7—healthcare)

From the respondents' comments, it is evident that there is no agreement on a common definition for intersex and for some, there is "not much of an understanding of the particularities of intersex versus the particularities of trans." (Respondent 10—healthcare)

This is significant, given that medical knowledge regarding intersex people directly affects hermeneutical injustice. Medical practitioners not only determine healthcare pathways on their assessment of whether or not someone has an intersex variation, but they are often responsible for conferring the knowledge necessary for that individual to make sense of their own lived experience. In a small country like Malta, having the doctors on board would mean also pushing cultural as well as medical visibility. Most of the respondents

were also unaware of any discussions held prior to the enactment of the law, particularly with the medical professions.

... remember consultations but not with medical personnel. (Respondent 3—advocacy) *I don't believe that there was any consultation with the medical profession*.... (Respondent 4—advocacy)

... when the law was drafted, they never talked to any doctors.... (Respondent 9—healthcare)

Although GIGESCA created more awareness for the trans community, both within the medical field and outside it, some of the respondents remarked that the same could not be said about the intersex community. Hoping that the law would bring about the same "momentum of change" for intersex people as it did for trans people, respondent 8 (healthcare) observed that "... it is useless making (sic) a law and then there is not awareness or training about it." While the general consensus is that many do not know much or enough about the law, some conflicting respondents still spoke of the increased amount of training that healthcare professionals were receiving about intersex and gender-related issues.

This highlights the hermeneutic difficulties with intersex issues. Despite legislation, healthcare professionals still lack the appropriate schematic tools to understand intersex variations outside the context of a disorder narrative (Garland and Travis 2023). More needs to be done to ensure that medical professionals understand the obligations placed upon them by GIGESCA. Reflection needs to be taken as to why the law has been so unsuccessful in interrupting medicines' conception of intersex as disorder. Nonetheless, Malta's stagnation supports Merrick's contention mentioned earlier that Western healthcare is ill-suited to listening to patient advocates. In this theme, a more general engagement with intersex people might create the environments needed to enable healthcare professionals to understand and make sense of intersex experiences.

#### 6. Improving Intersex Visibility

Malta provides evidence for those considering law reform in this area. The small island community in Malta and its conservative climate mean that some of our concerns are specific to Malta, while others are perhaps indicative of issues relating to the laws' discursive powers more generally. It is clear from our findings that political visibility, while necessary for law reform, is insufficient to transform and improve intersex experiences. The entrenched systemic nature of hermeneutical injustice and identity prejudice means that more must be done by states to create the conditions of change. Specifically, an integral part of challenging medical practice and enhancing the rights of intersex people relies on increasing the cultural visibility of intersex people, in tandem with specific legal regulation of the medical profession. Learning from Malta's experience, Law reformers and policy-makers must be attentive to hermeneutical injustice, particularly biomedical hermeneutical injustice, when pursuing ways in which to improve the lived experiences of intersex people. Political visibility, while important, is not sufficient to remedy the hermeneutical injustice gap.

Moreover, Malta reveals the vast obstacle that the schism between human rights and medical narratives can create when implementing law. States must think carefully about how they engage with various stakeholders to mitigate this standoff, and also ensure that the medical narrative does not dominate discussions about implementation. To remedy the divide between human rights and medical narratives, medical professionals must reflect on their own epistemic primacy and the privileging that their views are granted. In order to combat both hermeneutic and testimonial epistemic injustice, priority must be given to the voices and testimony of intersex people.

Visibility, in cultural, political and healthcare terms, must be the chief priority of reformers and requires continued engagement with relevant stakeholders after the introduction of legislation. In part, this will come from thinking creatively about ways to

legislate to improve intersex visibility, and therein, the possibility of future partnership. This will be easier in jurisdictions that have mobilised intersex organisations, support groups and communities. The lack of this in Malta necessitates more creative approaches. Medical treatment paradigms, as Merrick (2019) suggests, must be sufficiently informed by the testimony of intersex people, and this has proven to be challenging in Malta. Indeed, improving the visibility of intersex people was seen as a key priority for a number of our respondents. As Respondent 3 (advocacy) noted:

I would think that, one, we need to raise awareness, we need to raise a lot more awareness. We need to . . . As I said, most people—I'm not saying based on hard facts, but I would say that most people in Malta do not know what intersex is. They just don't know about it. So I think we would need to raise the awareness generally, and knowledge, so that it is not seen as something, such a taboo, such an out of the ordinary, extraordinary, a terrible place to be for somebody, but rather just part of life. Part of the diversity of life if you like. I would think that that would help, however I suspect that many, again completely off the top of my head, not based on any research or evidence, but I would think that people who are intersex may not think that that's a very good idea. Many people who are intersex, at the moment in Malta, who are living hidden lives, would, you know... I think they might find that very scary.

Awareness-raising through educative programs was mentioned by a number of our respondents. This would have value in breaking through the epistemic barriers many intersex people face in knowing themselves as intersex, and its value extends beyond Malta to those jurisdictions wanting to implement meaningful change. Awareness-raising offers the conceptual tools needed for self-identification and consequently self-acceptance. Such an approach would need buy-in from a range of institutions, including the education system, schools and individual teachers engaging in a 'whole-school learning approach' that encompasses the classroom, home and the local community (Brömdal et al. 2021). Education, therefore, might form an important part of challenging hermeneutical injustice and may be something for policy-makers to consider alongside the development of intersex legislation. Another method for improving intersex visibility would be through the development of community spaces and resources that can challenge the epistemic primacy of the healthcare profession. How this is done may need to be different in alignment with differing social and political contexts. Broadly speaking, however, the design and development of resources aimed at parents, or the placement of people with intersex variations on the potential multidisciplinary team, might go some way to raising the visibility of intersex people within medical spaces—not least to other intersex people. There are challenges with this approach, however, created by the lack of 'out' intersex people in Malta, but this may be less of a challenge in other jurisdictions. Malta's experience demonstrates how hermeneutical injustice is self-perpetuating. More research is needed with intersex populations in Malta to delve into this issue in greater depth.

Linked to this is the need for intersex role models within the 'media' space, specifically in Malta; some other jurisdictions have already begun these processes. These would go a long way to offering people schematic familiarity with intersex people across society. Once again, however, this encounters difficulties with a lack of visible intersex people within Malta. These challenges have yet to be addressed by Maltese policy-makers, and it may be that social norms around gender are so entrenched that this limits the speed and degree in which change can occur. Unfortunately, we have identified a lapse in momentum following the successful introduction of GIGESCA:

I would say either there's no political effort because again there's no pressure coming from anywhere barring possibly MGRM<sup>14</sup> and people like us. So there isn't that political pressure from above to hurry things up or get going. It sort of feels like there was this rush to get laws through and then once the dust had settled, it's done now you know, let's chill for a bit. . . . there's a sense of apathy coming from other parts, so . . . (Respondent 5—Law)

Again, this links back to the lack of a visible intersex-led organisation within Malta. The lack of existence of such an organisation, or indeed, any visible intersex stakeholders, has meant that there has been a lack of pressure on the Government to deliver on the promises contained within GIGESCA. Issues of heremenutic injustice continue to be cyclical and self-perpetuating, and intervention is desperately needed to break this cycle. Moreover, it points to the need to have an interconnected approach to challenge epistemic injustice that requires a clear road map that considers the various institutions that an individual may engage with across their lifetime. The recommendations that we make map onto one another: a successful education program may well lead to more role models and, in turn, greater community-building amongst intersex people who are given epistemic credibility about their concerns. Here, we highlight how gains in hermeneutic justice may eventually lead also to testimonial justice.

#### 7. Conclusions

In conclusion, this article offers empirical evidence to the growing acknowledgment of the relationship between intersex people, law and epistemic injustice (Merrick 2019; Carpenter 2018, 2023; Carpenter and Jordens 2022; Ziemińska 2020; Griffiths 2023). Our research is the first to demonstrate that whilst there has been political consciousness around intersex issues in Malta culminating in GIGESCA, this has seemingly failed to translate through to wider society and in parts of the healthcare system. Despite the development of promising legislation, intersex people continue to face epistemic injustice, and particularly hermeneutical injustice, at several levels. Hermeneutically, within Maltese culture, this has been particularly problematic, as many intersex people and their parents lack the schematic tools needed to conceptualise themselves or their children as intersex. As such, there has been a lack of engagement by intersex people with GIGESCA: our respondents struggled to think of a singular instance where an intersex person had engaged with the legislation and we were unsuccessful in our attempts to speak with intersex people themselves.

These issues are reinforced by feelings of shame or stigma that our respondents felt were heightened by the Maltese (conservative, Catholic) context. Moreover, intersex issues were often conflated with people's recognition of trans issues—an issue perhaps, with the duality of GIGESCA and the visibility of its significance for the trans community, perpetuating hermeneutical injustice.

Similarly, in terms of hermeneutical injustice, the lack of self-awareness of intersex people has fed into a broader pattern of cultural invisibility. There is a severe lack of intersex role models or 'out' community organisers in Malta. As such, much of the awareness-raising work has been picked up by broader LGBT+ organisations. This lack of representation perpetuates the cycle of invisibility and has stagnated the creation of a recognisable intersex community within Malta. Additionally, it continues the conflation of intersex and trans identities in the cultural consciousness (Garland and Travis 2020b, 2023).

This hermeneutical injustice is compounded by a medical profession that continues to frame intersex variations through the lens and terminology of disorder. At the same time, healthcare professionals' awareness of GIGESCA and the roles and legal obligations it placed upon them was limited—similarly pointing to continuing levels of hermeneutical injustice in one of the key populations the legislation was designed to respond to. More training was needed to counter healthcare professional's understandings of, and duties to, people with intersex variations.

As a result, we recommend that Malta undertake an extensive education program in order to tackle hermeneutic injustice—not just for medical professionals but across society through the education system. It is hoped that this will create the knowledge, context and conceptual tools necessary for intersex persons, parents and allies to identify themselves as intersex and to allow their injustices to be recognised. In the future, this may break the cycle of cultural invisibility and allow for a greater engagement with the intersex community in the creation of legal regulation and healthcare practices that center on justice for intersex people at their core.

Our findings have implications beyond the Maltese context. More broadly, those seeking to introduce legal reform must be attentive to the fact that law, alone, is insufficient to change the conditions of hermeneutical injustice. Commitment to improving the lived experiences of intersex people requires an extensive effort to ensure that intersex voices are heard, and that individuals and community representatives are able to actively participate and be listened to by institutional actors responsible for implementation and change post-legislation. Similarly, reformers need to ensure that there is an interconnected approach to challenging hermeneutical injustice, beginning with education. This, of course, will require tailoring to the specific context of that jurisdiction and the varied ways in which individuals engage with different institutions. It will also require working with international and, where possible, local organisations, and committing the necessary resources (financial and time) to change. Where there are no local organisations or role models, it highlights the greater need for investment in educational initiatives. In the long term, this will dismantle hermeneutical injustices and lead to the enabling of the intersex community.

Our final comment is that more research is desperately needed to capture the voices of intersex people, especially in Malta. While our findings offer some insight into the effects of law, it is by no means determinative, and the absence of intersex voices in this project mean that we are limited in the claims we can make.

**Author Contributions:** Conceptualization, F.G. and M.T.; methodology, F.G.; formal analysis, C.B.T., F.G. and M.T.; investigation, C.B.T., F.G. and M.T.; data curation, C.B.T., F.G. and M.T.; writing—original draft preparation C.B.T., F.G. and M.T.; writing—review and editing, C.B.T., F.G. and M.T.; project administration, F.G.; funding acquisition, F.G. and M.T. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by British Academy, grant number SRG19\_190990.

**Institutional Review Board Statement:** The study was conducted in accordance with the Declaration of Helsinki, and approved by the University of Manchester Research Ethics Committee 3 (Study Ref: 2021-7452-21286 approved 14 December 2021) and also the Maltese Health Ethics Committee (Study Ref HEC05.22. approved 05 August 2022).

**Informed Consent Statement:** Informed consent was obtained from all subjects involved in the study.

**Data Availability Statement:** Data supporting reported results will be deposited in the UK Data ReShare Depositary.

**Conflicts of Interest:** The authors declare no conflicts of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

#### Notes

- The study was unable to recruit intersex people. While this is a significant limitation it also indicates the extensiveness of epistemic injustice within Malta. We reflect on this further throughout.
- Endosex is the term coined to refer to people without intersex traits. See Carpenter et al. (2022).
- <sup>3</sup> *Joanne Cassar* v *Malta* Application no 36982/11.
- <sup>4</sup> For a detailed overview on the passage of this piece of legislation, see Garland and Travis (2023).
- See e.g., the individual response by Nicholas Briffa available here https://meae.gov.mt/en/public\_consultations/msdc/pages/consultations/gigesc.aspx (accessed on 8 November 2023).
- <sup>6</sup> Gender Identity, Gender Expression And Sex Characteristics Act (https://www.gov.mt) (accessed on 8 November 2023).
- The composition of this team was not set within GIGESCA, but rather was to be "composed of those professionals whom the Minister considers as appropriate".
- We reflect more on the relationship between terminology and epistemic injustice in Section 5.1.
- 9 e.g., we removed details such as familial relationships and living relationships, religious or cultural background.
- Hypospaidas is where the urethalopening is not at the tip of the penis.

Their consultation response can be found here: https://meae.gov.mt/en/Public\_Consultations/MSDC/Documents/2014%20-%20GIGESC/Organisation%20Intersex%20International%20Australia%20(OII%20Australia).pdf (accessed on 8 November 2023).

- Other projects have similarly encountered difficulties with recuritment and Ní Mhuirthile et al. (2022) have identified intersex as a 'hard-to-reach' population.
- We had taken measures to mitigate for the heightened risks with anonymity, following Saunders et al. (2015) for research conducted in small island communities.
- <sup>14</sup> A Maltese based organisation devoted to achieving "full equality for LGBTIQ people in Maltese society". <maltagayrights.org>

#### References

Ballakrishnen, Swethaa, and Sarah B. Lawsky. 2022. Law, Legal Socializations, and Epistemic Injustice. Law & Social Inquiry, FirstView, 2022, forthcoming, UC Irvine School of Law Research Paper No. 2022-19. Available online: https://ssrn.com/abstract=4130483 (accessed on 1 September 2023).

Braune, Virginia Braun, and Victoria Clarke. 2015. Using Thematic Analysis in Psychology. *Qualitative Research in Psychology* 3: 77–101. [CrossRef]

Brömdal, Annette, Agli Zavros-Orr, Lisahunter, Kirstine Hand, and Bonnie Hart. 2021. Towards a wholeschool approach for sexuality education in supporting and upholding the rights and health of students with intersex variations. *Sex Education* 21: 568583. [CrossRef]

Butler, Judith. 1990. Gender Trouble, Routledge Classics. London: Routledge.

Carpenter, Morgan. 2018. The "Normalization" of Intersex Bodies and "Othering" of Intersex Identities in Australia. *Journal of Bioethical Inquiry* 15: 487–95. [CrossRef] [PubMed]

Carpenter, Morgan. 2023. Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands. *Clinical Ethics* 115. [CrossRef]

Carpenter, Morgan, and Christopher F. C. Jordens. 2022. When Bioethics Fails: Intersex, Epistemic Injustice and Advocacy. In *Interdisciplinary and Global Perspectives on Intersex*. Edited by Megan Walker. Cham: Springer Nature Switzerland AG.

Carpenter, Morgan, Katharine B. Dalke, and Brian D. Earp. 2022. Endosex. *Journal of Medical Ethics* 49: 225–26. [CrossRef] [PubMed] Davis, Georgiann. 2015. *Contesting Intersex: The Dubious Diagnosis*. New York: NYU Press.

Dreger, Alice. 1998. Hermaphrodites and the Medical Invention of Sex. Harvard: Harvard University Press.

Falzon, Neil. 2010. A Proposed Gender Identity Act for Malta. Available online: https://issuu.com/aditus/docs/a\_proposed\_gender\_identity\_act\_for\_malta\_?mode=embed&layout=http://skin.issuu.com/v/light/layout.xml&showFlipBtn=true (accessed on 1 September 2023).

Foucault, Michel. 1980. Herculine Barbin: Being the Recently Discovered Memoirs of a Nineteenth-Century French Hermaphrodite. New York: Pantheon Books.

Fredman, Sandra. 2016. Substantive equality revisited. International Journal of Constitutional Law 14: 712-38. [CrossRef]

Fricker, Miranda. 2007. Epistemic Injustice: Power and the Ethics of Knowing. Oxford: Oxford University Press. ISBN 9780198237907.

Fricker, Marianne. 2017. Evolving concepts of epistemic injustice. In *Routledge Handbook of Epistemic Injustice*. Edited by Ian James Kidd, Jose Medina and Gaile Pohlhaus, Jr. Routledge Handbooks in Philosophy. London: Routledge, pp. 53–60. ISBN 9781138828254.

Garland, Fae, and Mitchell Travis. 2018. Legislating intersex equality: Building the resilience of intersex people through law. *Legal Studies* 38: 587–606. [CrossRef]

Garland, Fae, and Mitchell Travis. 2020a. Making the State Responsible: Intersex Embodiment, Medical Jurisdiction and State Responsibility. *Journal of Law and Society* 47: 298–324. [CrossRef]

Garland, Fae, and Mitchell Travis. 2020b. A Jurisprudence of the Body: Emergencies, Emergence, and Intersex Embodiment. In *A Jurisprudence of the Body*, 1st ed. London: Palgrave Macmillan Ltd.

Garland, Fae, and Mitchell Travis. 2023. *Intersex Embodiment Legal Frameworks beyond Identity and Disorder*. Bristol: Bristol University Press. ISBN 9781529217391.

Garland, Fae, Kay Lalor, and Mitchell Travis. 2022. Intersex Activism, Medical Power/Knowledge and the Scalar Limitations of the United Nations. *Human Rights Law Review* 22: ngac020. [CrossRef]

Goldberg, Daniel. 2020. Epistemic Injustice, Disability Stigma, and Public Health Law. In *Disability, Health, Law and Bioethics*. Cambridge: Cambridge University Press.

Griffiths, David Andrew. 2023. Georgina Somerset, British Intersex history, and the I in LGBTQI. *Journal of Homosexuality* 23: 1–24. [CrossRef]

Hegarty, Peter, and Cheryl Chase. 2000. Intersexed activism, feminism, and psychology: Opening a dialogue on theory, research, and practice. Feminism & Psychology 10: 117–32. [CrossRef]

Hegarty, Peter, Marta Prandelli, Tove Lundberg, Lih-Mei Liao, Sarah Creighton, and Katrina Roen. 2021. Drawing the line between essential and non-essential interventions on intersex characteristics with European healthcare professionals. *Review of General Psychology* 25: 101–14. [CrossRef]

Holmes, Morgan. 2011. "The Intersex Enchiridion: Naming and Knowledge". Somatechnics 1: 388-411. [CrossRef]

Lee, Peter A., Christopher P. Houk, S. Faisal Ahmed, Ieuan 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: e488–e500. [CrossRef] [PubMed]

Lundberg, Tove, Katrina Roen, Carina Kraft, and Peter Hegarty. 2021. How young people talk about their variations in sex characteristics: Making the topic of intersex talkable via sex education. Sex Education 21: 1–16. [CrossRef]

Luzzi, Federico. 2021. Deception-Based Hermeneutical Injustice. Episteme, 1–9. [CrossRef]

Malatino, Hilary. 2019. *Queer Embodiment: Monstrosity, Medical Violence, and Intersex Experience*. Lincoln: University of Nebraska Press. Merrick, Teri. 2019. From 'Intersex' to 'DSD': A case of epistemic injustice. *Synthese* 196: 4429–47. [CrossRef]

Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffiths, Peter Hegarty, Mitchell Travis, Mauro Cabral Grinspan, and Peter Aggleton. 2021. Intersex: Cultural and social perspectives. *Culture, Health & Sexuality* 23: 431–40. [CrossRef]

Ní Mhuirthile, Tanya. 2018. Malta. In *The Legal Status of Intersex Persons*. Edited by Jens Scherpe, Anatol Dutta and T. Helms. Cambridge: Intersentia, pp. 357–68. [CrossRef]

Ní Mhuirthile, Tanya, Maria Feeney, Mel Duffy, and Anthony Staines. 2022. *Mapping the Lived Experiences of Intersex/Variations of Sex Characteristics in Ireland: Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy*. Dublin: Dublin City University, pp. 1–242.

Preves, Sharon. 2003. Intersex and Identity: The Contested Self. New Brunswick: Rutgers University Press.

Roen, Katrina, Tove Lundberg, Peter Hegarty, and Lih-Mei Liao. 2023. Whose responsibility is it to talk with children and young people about intersex/differences in sex development? Young people's, caregivers' and health professionals' perspectives. Frontiers in Urology 3: 1089198. [CrossRef]

Saunders, Benjamin, Jenny Kitzinger, and Celia Kitzinger. 2015. Anonymising interview data: Challenges and compromise in practice. *Qualitative Research* 15: 616–32. [CrossRef]

Streuli, Jürg C., Effy Vayena, Yvonne Cavicchia-Balmer, and Johannes 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: 1953–60. [CrossRef] [PubMed]

Topp, Sarah S. 2013. Against the quiet revolution: The rhetorical construction of intersex individuals as disordered. *Sexualities* 16: 180–94. [CrossRef]

Viloria, Hida. 2017. Born Both: An Intersex Life. Boston: Hachette.

Ziemińska, Renata. 2020. The Epistemic Injustice Expressed in 'Normalizing' Surgery on Children With Intersex Traits. *Diametros* 17: 52–65. [CrossRef]

**Disclaimer/Publisher's Note:** The statements, opinions and data contained in all publications are solely those of the individual author(s) and contributor(s) and not of MDPI and/or the editor(s). MDPI and/or the editor(s) disclaim responsibility for any injury to people or property resulting from any ideas, methods, instructions or products referred to in the content.