D20 eReport on policymaking in the EU

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Intersex issues and policymaking in the EU

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1. Introduction and Background

'Intersex' refers to people born with a combination of sex characteristics (chromosomal, gonadal and/or anatomical[1]) that do not fit the typical definitions of male or female[2]. Intersex is always congenital and can originate from genetic, chromosomal, or hormonal variations. It may be a combination of all three elements. Environmental influences such as endocrine disruptors can also play a role in some intersex differences[3]. The United Nations estimates that between 0.05% and 1.7% of infants are born with intersex traits[4]. Some variations of sex characteristics, including hypospadias, are not always considered to be intersex, hence the variation in figures. Within a medical context, there are up to 40 sex variations including Androgen Insensitivity Syndrome, 46 XY Gonadal Dysgenesis, 5-ARD, Congenital Adrenal Hyperplasia, and 46 XX Testicular Difference of Gonadal Sex[5].

The term 'Disorders of Sex Development' was introduced in the Chicago Consensus Statement 2006[6] and subsequently this term, and the term 'Differences of Sex Development' are used in medical settings for people who are intersex and/or have Variations of Sex Characteristics. Intersex people usually reject the use of the term 'Disorders of Sex Development' because it is pathologising[7]. However, this term is relevant because many patient groups reject the idea of 'intersex' and see people with sex variations as having specific conditions, rather than having intersex as an identity. This rejection of 'intersex' as an identity and the related efforts to keep intersex a secret can be seen as attempts to avoid homophobia and transphobia as well as distance from other groups facing social discrimination, notably LGBT people. For this report, the broader category of 'variations of sex characteristics' will be added to the term 'intersex'. Other terms adopted by intersex people and their allies such as "Sex Diversity" and 'Variations of Sexual Development' highlight the array of identities that exist among this population[8].

Intersex people face high levels of discrimination based on their sex characteristics. Discrimination in medical settings is extreme, including selective termination of foetuses with sex variations. Medically unnecessary genital surgeries on infants and children where the infant/child has not given consent due to age are still commonly practised and, in some cases, this happens without parental consent[9]. Invasive examinations, genital sensitivity testing, and

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[1] Including hormone receptor variants.

[2] Lee, P. A., Houk, C. P., Ahmed, S. F., Hughes, I. A., & International Consensus Conference on Intersex organised by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology (2006). Consensus statement on management of intersex disorders. International Consensus Conference on Intersex. *Pediatrics*, *118*(2), e488–e500. https://doi.org/10.1542/peds.2006-0738

[3] OII-United Kingdom. (n.d.). https://oiiuk.org/

[4] United Nations for LGBT Equality. (2017). *Fact sheet: Intersex*. https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf

[5] Petersen, J.K. (2021). *A Comprehensive Guide to Intersex*. Jessica Kingsley Publications.

[6] Hughes, I. A., Houk, C., Ahmed, S. F., Lee, P. A., LWPES Consensus Group, & ESPE Consensus Group (2006). Consensus statement on management of intersex disorders. *Archives of Disease in Childhood, 91*(7), 554–563. http://www.aissg.org/PDFs/Chicago-Consensus-Statement-06.pdf

[7] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change*. University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/33535/

[8] Crocetti, D., Monro, S., Vecchietti, V., & Yeadon-Lee, T. (2021). Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health. *Culture, health & sexuality*, *23*(4), 500–515. https://doi.org/10.1080/13691058.2020.1825815

[9] European Union Agency for Fundamental Rights. (2020). *A long way to go for LGBTI equality*. Publications Office of the European Union. https://data.europa.eu/doi/10.2811/7746

forced neo-vaginal dilation are performed on some intersex children. The medically unnecessary removal of gonads is also an issue, depriving intersex people of reproductive rights. As a result of unnecessary early medical interventions, intersex people report a wide range of harms including scarring and the need for repeat surgeries, damage to sexual wellbeing, serious mental health problems, and long-term hormone dependence with related health risks. The outcomes of surgical procedures and medication on babies and children with sex variations are typically reported as being poor and/or damaging[10]. Research indicates that over 60% of intersex people in the EU have had one or more surgeries that they did not give consent for and that almost 70% of parents who gave consent for surgeries had not received detailed information before the surgery took place[11].

The socioeconomic position of many intersex people in the EU is often very difficult and intersex people can face discrimination in their wider social lives. Levels of social prejudice are high but vary considerably across the EU Member States[12]. Social invisibility is a problem[13] which can be linked with secrecy, shame, and the perpetuation of damaging medical practices[14]. For example, a study of attitudes in the Dutch and Flemish populations showed that 52% of respondents did not know what ‘intersex’ meant[15]. Almost two-thirds of intersex respondents in the second FRA LGBTI survey[16] felt discriminated in at least one area of life due to being intersex. Birth registration discrimination occurs in most Member States, where parents are legally obliged to register their child at birth as either male or female, with no X or other option being available[17]. Older intersex people also face several potential disadvantages regarding social support in later years. Increased risk of loneliness is similarly likely for a plethora of reasons[18].

Because intersex is not included in the list of protected characteristics in terms of legal protections from discrimination in some countries (e.g. Ireland and England), people with

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[10] Creighton, S. M., Minto, C. L., & Steele, S. J. (2001). Objective cosmetic and anatomical outcomes at adolescence of feminising surgery for ambiguous genitalia done in childhood. *The Lancet, 358*(9276), 124-125; Lorenzo, A. J., Pippi Salle, J. L., Zlateska, B., Koyle, M. A., Bägli, D. J., & Braga, L. H. (2014). Decisional regret after distal hypospadias repair: single institution prospective analysis of factors associated with subsequent parental remorse or distress. *The Journal of Urology*, *191*(5 Suppl), 1558–1563. https://doi.org/10.1016/j.juro.2013.10.036; Diamond, M., & Garland, J. (2014). Evidence regarding cosmetic and medically unnecessary surgery on infants. *Journal of Pediatric Urology, 10*(1), 2-6.

[11] Russell, C., Amoroso, I., Hugo, J., Kromminga, I. (2023). *Diving into the FRA LGBTI II Survey Data: Intersex Briefing*. https://www.ilga-europe.org/files/uploads/2023/05/FRA-Intersections-Report-Intersex.pdf

[12] European Commission. (2019). *Eurobarometer on the social acceptance of LGBTIQ people in the EU*. https://ec.europa.eu/info/policies/justice-and-fundamental-rights/combatting-discrimination/lesbian-gay-bi-trans-and-intersex-equality/eurobarometer-social-acceptance-lgbtiq-people-eu-2019_en

[13] Agius, S. (2017). *Human rights and intersex people*. Council of Europe Commissioner for Human Rights. https://rm.coe.int/16806da5d4

[14] Crocetti, D., Monro, S., Vecchietti, V., & Yeadon-Lee, T. (2021). Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health. *Culture, health & sexuality*, *23*(4), 500–515. https://doi.org/10.1080/13691058.2020.1825815

[15] van Ditzhuijzen, J. & Motmans, J. (2020). *Kennis en opvattingen over intersekse: Een nulmeting in Nederland en Vlaanderen. Rutgers & UZ Gent*. https://rutgers.nl/wp-content/uploads/2021/09/Rapport_Nulmetingintersekse_REVISED.pdf

[16] European Union Agency for Fundamental Rights. (2020). *A long way to go for LGBTI equality*. Publications Office of the European Union. https://data.europa.eu/doi/10.2811/7746

[17] European Union Agency for Fundamental Rights. (2015). The fundamental rights situation of intersex people. https://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people#publication-tab-18

[18] Hughes, M. (2016). Loneliness and social support among lesbian, gay, bisexual, transgender and intersex people aged 50 and over. *Ageing & Society, 36*(9), 1961–1981. https://doi.org/10.1017/S0144686X1500080X

variations of sex characteristics are vulnerable to discrimination[19]. For example, if they need to take medical leave from employment, they cannot access rights in the same way that a transgender person undergoing gender confirmation surgery can in some Member States. Protection from discrimination is enshrined in EU Treaties such as the Charter of Fundamental Rights of the European Union (Article 21) and Directive 2000/78/EC and the related secondary legislation. Intersex people can be protected under the ground of 'sex characteristics', but there is no case law yet to support this.

Appropriate access to healthcare is a significant issue for intersex people. As the HEALTH4LGBTI research showed, stigmatisation and barriers to healthcare and social care services persist for the LGBTI population more broadly[20]. In the EUCIT and INIA projects, we found that access to appropriate healthcare was critical to intersex people[21]. Some of the intersex contributors reported issues such as avoidance of healthcare due to previous trauma in healthcare settings, and experiences of discriminatory behaviours amongst healthcare professionals such as intrusive questioning about intersex conditions when the problem presented had nothing to do with intersex. We also found a lack of specialist knowledge, equipment (for example, catheters of the right size), and expert knowledge for intersex people needing treatment. This was often reparative treatment due to previous medical abuse, such as the management of damaging surgeries, or hormonal requirements due to the removal of gonads. However, because some management of ongoing conditions is often needed by intersex people whether this is because of the effects of non-vital surgeries or for other reasons, access to healthcare is crucially important.

Education can be a particular area of difficulty for intersex people for several reasons, such as high levels of bullying, worries about taking part in subjects such as physical education, and potentially being 'outed' as having a sex variation. The impact of repeated medical interventions on educational attainment is very problematic, as children may miss substantial periods of education due to illness caused in some cases by non-vital medical interventions[22]. Another problem is that intersex issues are often excluded from school curricula; for example, biology lessons may promote the idea that there are only two sexes, which have typical male or female sex characteristics. The 2019 Eurobarometer showed varied opinions across the Member States regarding the inclusion of intersex in school curricula, with some States showing less than 50% support for this[23].

The Council of Europe and the European Parliament have played a leading role in recognising that intersex people in the EU are subject to widespread human rights violations and are

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[19] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change*. University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/33535/

[20] European Commission. (n.d.). *Health4LGBTI: Reducing health inequalities experienced by LGBTI people*. https://health.ec.europa.eu/social-determinants/projects/european-parliament-projects_en

[21] Crocetti, D., Monro, S., Vecchietti, V., & Yeadon-Lee, T. (2021). Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health. *Culture, health & sexuality*, *23*(4), 500–515. https://doi.org/10.1080/13691058.2020.1825815

[22] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change*. University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/33535/

[23] European Commission. (2019). *Eurobarometer on the social acceptance of LGBTIQ people in the EU*. https://ec.europa.eu/info/policies/justice-and-fundamental-rights/combatting-discrimination/lesbian-gay-bi-trans-and-intersex-equality/eurobarometer-social-acceptance-lgbtiq-people-eu-2019_en

developing measures to address discrimination[24]. In particular, violations include Intersex Genital Mutilation (IGM), the imposition of other non-vital medical interventions on minors, and a lack of state protection from such abuses[25]. The United Nations recognises that medically unnecessary surgeries and other procedures on intersex children before they can provide informed consent constitute harmful practices, and they make several recommendations[26] including State enactment of legislation to prohibit these practices. Human rights violations faced by intersex people can also be framed using the Yogyakarta Principles[27] and Yogyakarta Principles plus 10[28], including:

- Principle 10: Relating to the Right to Freedom from Torture and Cruel, Inhuman or Degrading Treatment or Punishment
- Principle 18: Protection from Medical Abuse
- Principle 30: The Right to State Protection
- Principle 32: The Right to Bodily and Mental Integrity
- Principle 37: The Right to Truth

NGOs have also played crucial roles in initiating and supporting policy reform. Notably, OII Europe has produced a range of policy resources such as a toolkit for policy makers.[29]

Despite the frameworks produced at the EU levels, it has been difficult to implement human rights for intersex people at national levels. In some EU Member States, the majority of the population thinks that intersex people should have equal rights (for instance the Netherlands[30]) showing that there may be possibilities for improvement. Whilst Malta, and more recently Portugal, are notable exceptions in having stipulated protections for intersex minors, national legislation is lagging in most nations, and there is a pressing need for research about the

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[24] See for example Agius, S. (2017). *Human rights and intersex people*. Council of Europe Commissioner for Human Rights. https://rm.coe.int/16806da5d4; European Commission. (2020). *Communication from the Commission to the European Parliament, the Council, The European Economic and Social Committee and the Committee of the Regions Union of Equality: LGBTIQ Equality Strategy 2020-2025*. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52020DC0698 and *Promoting the human rights of and eliminating discrimination against intersex people, Resolution 2191*, Parliamentary Assembly. (2017). http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24232

[25] See Ghattas, D. (2013). *Human Rights between the Sexes: A Preliminary Study on the Life Situations of Inter* Individuals*. Heinrich-Boll-Stiftung. https://www.boell.de/sites/default/files/endf_human_rights_between_the_sexes.pdf; Carpenter, M. 2016. 'The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change.' *Reproductive Health Matters, 24*(47): 74-84. https://doi.org/10.1016/j.rhm.2016.06.003.

[26] Office of the High Commissioner for Human Rights. (2019). *Background Note on Human Rights Violations against Intersex People*. https://www.ohchr.org/EN/Issues/Discrimination/Pages/BackgroundViolationsIntersexPeople.aspx

[27] The Yogyakarta Principles. (2007). *Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity*. http://yogyakartaprinciples.org/wp-content/uploads/2016/08/principles_en.pdf

[28] Grinspan, M., Carpenter, M., Ehrt, J., Kara, S., Narrain, A., Patel, P., Sidoti, C., & Tabengwa, M. (2017). *The Yogyakarta Principles plus 10: Additional Principles and State Obligations on the Application of International Human Rights Law in relation to Sexual Orientation, Gender Identity, Gender Expression, and Sex Characteristics to complement the Yogyakarta Principles*. http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf

[29] Ghattas, D. (2019). *Protecting Intersex People in Europe: A Toolkit for Law and Policymakers (with digital appendix and checklist)*. ILGA Europe & OII Europe. https://oiieurope.org/wp-content/uploads/2019/05/Protecting_intersex_in_Europe_toolkit.pdf

[30] van Ditzhuijzen, J. & Motmans, J. (2020). *Kennis en opvattingen over intersekse: Een nulmeting in Nederland en Vlaanderen. Rutgers & UZ Gent*. https://rutgers.nl/wp-content/uploads/2021/09/Rapport_Nulmetingintersekse_REVISED.pdf

effects of this on intersex people. There are resources available, often developed by intersex NGOs, but take-up of these by governments is limited.[31]

2. Aims and caveats

This report showcases relevant findings derived from fieldwork and documentary analysis, conducted as part of the INIA Innovative Training Network, titled "Intersex - New Interdisciplinary Approaches (2020-2024)" project. The report aims to provide materials and analysis for policy makers, practitioners and interested laypeople in the areas of social policy and intersex people and those with variations of sex characteristics. Human rights and legal issues are of course central to policy making. However, these are addressed in other INIA outputs[32] (and elsewhere[33]), so the report does not focus on them here per se. The report is intended to be partial and indicative, given the great need for more policy work in this field. Addressing the large medical literature[34] is outside of the scope of the report, although the INIA project does contribute to policy-relevant knowledge about multi-disciplinary teams[35]. While the focus of the report is on the EU, it includes material from England in the Case Study section, as England was included as a comparator country to Ireland for the project on which that section is based (Early Career Research Project 2).

The report uses 'intersex' as the main term but in some places, the term Variations of Sex Characteristics (VSC) are also used, to reflect the diversity of attitudes towards terminology found in the field. The terms Disorders of Sex Development (DSD) and differences of sex development (dsd) are not used, but it is recognised that these are commonly used within medical settings.

The report starts with a short review of key literatures relevant to the EU. Next, it provides analysis of intersex people's issues and equality, diversity and inclusion (EDI), covering some key background issues, using Ireland and England as case studies. The report then focuses on the case studies of Ireland and England, employing a poststructuralist analysis to revel the erasure of intersex issues in policy documents and providing key findings from cross-sectoral research. The report then provides cross-sectoral recommendations based on synthesis of all

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[31] Ghattas, D. (2019). *Protecting Intersex People in Europe: A Toolkit for Law and Policymakers (with digital appendix and checklist)*. ILGA Europe & OII Europe. https://oiieurope.org/wp-content/uploads/2019/05/Protecting_intersex_in_Europe_toolkit.pdf

[32] Zelayandia-Gonzalez, E. (2023). The growing visibility of intersex demands at the United Nations: A review of the treaty bodies' concluding observations. *Social Sciences (Basel), 12*(2), 73. https://doi.org/10.3390/socsci12020073; Mestre, Y. (2022). The Human Rights Situation of Intersex People: An Analysis of Europe and Latin America. *Social Sciences, 11*(7), 317. http://dx.doi.org/10.3390/socsci11070317; Lum, S. (2021). Intersex framings within international human rights law. https://doi.org/10.5281/zenodo.7476864

[33] Rubashkyn, E. & Savelev, I. (2023). *Intersex Legal Mapping Report: Global Survey on Legal Protections for People Born with Variations in Sex Characteristics*. ILGA World. https://ilga.org/downloads/ILGA_World_Intersex_Legal_Mapping_Report_2023.pdf?fbclid=IwAR3WvaVW70iHx1wZPpv4n_h2M3FaB9O0KVc_U4H1-1ummbtTXdRyvhjBLyQ

[34] Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., Baratz Dalke, K., Liao, L. M., Lin-Su, K., Looijenga, L. H., 3rd, Mazur, T., Meyer-Bahlburg, H. F., Mouriquand, P., Quigley, C. A., Sandberg, D. E., Vilain, E., Witchel, S., & Global DSD Update Consortium (2016). Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone research in paediatrics*, *85*(3), 158–180. https://doi.org/10.1159/000442975

[35] Gramc, M., Streuli, J., de Clercq, E. (2021). Multidisciplinary teams caring for people with variations of sex characteristics: a scoping review. *BMJ Paediatrics Open* 2021(**5),** e001257. https://bmjpaedsopen.bmj.com/content/5/1/e001257

10 INIA projects. These recommendations are also available as individual briefs via the INIA websitehttps://www.intersexnew.co.uk/project-publications/.

3. Key recent publications regarding policy reform

There are a number of sources available regarding policy reform, intersex people and those with variations of sex characteristics. The European Commission LGBTIQ Equality Strategy[36] 2020-2025 is a key document, including measures to increase action, and to integrate and mainstream LGBTIQ equality into every policy area. Importantly, it foregrounds the strength that comes from having diverse societies, whilst acknowledging that discrimination against LGBTIQ people is increasing in the EU overall. It takes an intersectional approach, recognising how variations of sex characteristics are interrelated with other aspects of identity such as race/ethnic origin and disability.

The report picks out areas specific to policy that may previously have been overlooked, for example, it notes discriminatory attitudes amongst general populations towards intersex people [37]. The progress report on its implementation[38] used consultation with EU Member States and it recommends enhancing the role of equality bodies and discusses national action plans and legal measures to tackle discrimination, reporting that the large majority of measures in the LGBTIQ strategy have been, or are being, delivered. Employment discrimination is a key concern, something that was reflected in the INIA research findings, especially in the Older Peoples project which revealed experiences of economic marginalisation and its impact. The report also highlights issues concerning personal safety, as the FRA survey[39] which found that trans and intersex people experience high levels of physical and sexual assault. Analysis of the report shows that more policy work specific to intersex people would be useful in the future. Amalgamating Intersex into the LGBTIQ umbrella can be helpful in making some space for intersex people's issues, and many discriminations that LGBT people face (such as hate crimes) are also experienced by intersex populations, but there is a risk of overlooking the specific experiences of intersex people.

In 2023, the European Commission against Racism and Intolerance adopted a policy recommendation on preventing and combatting intolerance and discrimination against LGBTI persons that explicitly includes intersex people[40]. This directly addresses the problems of intersex erasure in social policies. The report foregrounds issues such as the lack of reliable data about intersex people, the limited successes in cessation of so-called 'sex-normalising' procedures that are regularly done on children with sex variations without their informed consent, and the lack of legal protections in most European states. The report also addresses issues that affect intersex people as well as non-intersex LGBT people, such as barriers to

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[36] European Commission. (2020). LGBTIQ Equality Strategy 2020-2025. https://commission.europa.eu/document/5100c375-87e8-40e3-85b5-1adc5f556d6d_en

[37] European Commission. (2020). *Communication from the Commission to the European Parliament, the Council, The European Economic and Social Committee and the Committee of the Regions Union of Equality: LGBTIQ Equality Strategy 2020-2025*. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52020DC0698

[38] European Commission. (2023). *On the implementation of the LGBTIQ Equality Strategy 2020-2025*. Publications Office of the European Union. https://commission.europa.eu/system/files/2023-04/JUST_LGBTIQ%20Strategy_Progress%20Report_FINAL_WEB.pdf

[39] European Union Agency for Fundamental Rights. (2020). *A long way to go for LGBTI equality*. Publications Office of the European Union. https://data.europa.eu/doi/10.2811/7746

[40] Council of Europe. (2023). *ECRI Report on Poland*. https://rm.coe.int/sixth-ecri-report-on-poland/1680ac8c62

seeking asylum (for refugees) and the very negative impact of anti-gender rhetoric and movements on LGBTI people.

Country-specific reports are also available, for example, the ECRI report on Poland which includes policy issues more broadly (such as those affecting migrants and the Roma population). This report raises concerns about the equality infrastructures in Poland, within the context of broader concerns with equality infrastructures across Europe. Concerning the LGBTI population, the report states that aspects of LGBT equality were included in the National Programme for Equal Treatment 2021-20230 but also highlights cultures and municipality-led practices of hostility to the LGBTI communities. The report contains some material specific to intersex people, including information about the lack of specialised healthcare facilities for adults. It reports discriminatory treatment in schools and faith settings. Importantly, the report recommends that the authorities act to address the following:

> ‘i) The introduction of specific legislation prohibiting medically unnecessary sex-“normalising” surgery and other non-therapeutic treatments until such a time as the intersex child is able to participate in the decision, based on the right to self-determination and on the principle of free and informed consent, ii) the development of guidelines and training on intersex equality rights for relevant professionals, especially those coming into contact with intersex children, such as teachers and healthcare professionals, iii) encourage religious leaders at all level to avoid fuelling interphobia and prevent intolerance and discrimination against intersex children and iv) the dissemination of relevant materials to the people concerned, such as guides for the parents of intersex children.’[41]

As noted above, NGOs have also made significant contributions to and/or have led moves to reform policy regarding intersex people. For example, recently, OII Europe together with ILGA EUROPE published a briefing about the FRA LGBTI II survey’s results on intersex people[42]. They show that intersex people are often not open about their identities. The survey report shows very high levels of socioeconomic marginality, for example over 25% of survey respondents had difficulty or great difficulty meeting their basic household/living financial needs, and over 34% had had housing difficulties, with higher rates for those with disabilities and/or migrant and minority backgrounds. Barriers to financial and housing security include direct discrimination and the adversity caused by trauma-related poor educational achievement. Over 40% of respondents also reported discrimination in health or social care settings. However, intersex respondents were less likely than other groups to report discrimination or seek redress. Overall, this analysis shows a pattern of severe and entrenched discrimination and marginalisation. Marginalisation and a lack of visibility can serve as a barrier to policymakers and public officials addressing the needs of the population they serve; these issues are compounded and reinforced by the erasure of intersex issues and people in policy documents and discourse, as indicated above.

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[41] Council of Europe. (2023). *ECRI Report on Poland*. https://rm.coe.int/sixth-ecri-report-on-poland/1680ac8c62

[42] Russell, C., Amoroso, I., Hugo, J., Kromminga, I. (2023). *Diving into the FRA LGBTI II Survey Data: Intersex Briefing*. https://www.ilga-europe.org/files/uploads/2023/05/FRA-Intersections-Report-Intersex.pdf

4. Intersex people and Equality, Diversity and Inclusion

This section of the report provides an overview of how Equality, Diversity and Inclusion (EDI) policies have developed with a specific focus on the Irish and English cases. EDI policies are developed across different countries in various ways, and some non-EU materials are included here, as policy interventions circulate globally.

Within the INIA project, Work Package 6 specifically addressed social policy. Early Career Projects 2 and 8 employ a critical poststructuralist methodology of policy analysis, as developed by Bacchi[43], to explore the intersection of intersex issues and policy formulation. The analytical framework employed, termed 'What is the Problem Represented to Be?' (WPR), serves to unveil the underlying assumptions, discourses, and omissions embedded within existing policies. This method sheds light on how these policies either perpetuate or challenge the prevailing status quo. As one aspect of this form of analysis, we examined how EDI policies developed over time, and why intersex people are so often excluded from them. Within the field of social policy, EDI policies are often used as a mechanism for ensuring that people from vulnerable populations are included within the various sectors that social policy addresses (such as welfare programmes, education, employment, leisure and sport, the media, and healthcare).

Equality policies in England, which were developed after the Second World War, initially addressed disability[44] and were advanced by protest movements that did not include intersex people's concerns per se[45]. At first, equal opportunities aimed to tackle inequalities related to welfare and employment[46]. Aspects of this, such as appropriate healthcare provision, could have been useful to intersex people, but medical institutions were moving in the opposite direction, entrenching the erasure of intersex and the assimilation of intersex people within a binary sex and gendered system. The linking of equal opportunities with diversity around 2000 acknowledged intersectionality and the possibility that different groups had varied requirements[47]. This would have been relevant to intersex people, who are a heterogenous group with many intersectional issues, for example, an intersex person might be disabled, female, and young, as well as intersex. However, intersex people remained invisible at this stage and in the subsequent development of EDI policies[48]. There are strong rationales for EDI policies[49] which include the moral case for social justice (it is fair that intersex people are treated equally), the business case (intersex people will contribute more to society if properly included) and the social cohesion case (violence and conflict are more likely in unequal societies).

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[43] Bacchi, C. (1999). *Women, Policy and Politics: The Construction of Policy Problems*. Sage.; Bacchi, C. L., & Goodwin, S. (2016). *Poststructural policy analysis: A guide to practice*. http://doi.org/10.1057/978-1-137-52546-8_1

[44] Bagilhole, B (1997) *Equal opportunities and social policy: Issues of gender, race and disability.* Longman.

[45] See Richardson, D. & Monro, S. (2012) *Sexuality, equality and diversity.* Palgrave MacMillan.

[46] Bagilhole, B. (1997). *Equal opportunities and social policy: Issues of gender, race and disability.* Longman.

[47] Bagilhole, B. (2009). *Understanding equal opportunities and diversity: The social differentiations and intersections of inequality* (1st ed.). Bristol University Press. https://doi.org/10.2307/j.ctt1t89d53

[48] Garg, S., & Sangwan, S. (2021). Literature Review on Diversity and Inclusion at Workplace, 2010–2017. *Vision*, *25*(1), 12-22. https://doi.org/10.1177/0972262920959523

[49] Bagilhole, B. (2009). *Understanding equal opportunities and diversity: The social differentiations and intersections of inequality* (1st ed.). Bristol University Press. https://doi.org/10.2307/j.ctt1t89d53

Individualistic approaches to intersex EDI are critical given the importance that intersex people give to issues of bodily autonomy and self-determination[50]. The more structural stances adopted by earlier equalities policies, which looked at group-based inequalities at a systemic level are also necessary, given endemic interphobia (prejudice against intersex people) and endosexism (assumptions that everyone is non-intersex) in social policy spheres. However, intersex people have been overlooked by structural approaches to equalities as well.

The equalities work of the 1970s-2000 period could well lend itself to unpacking the structural, patriarchal, gender and sex-binaried underpinnings of intersex people's oppression. The core thinking, of linking social inequalities with institutional sexism, is there. However, gender equality policies from the start were concerned with women's inequality, and assumptions were made that gender related only to males and females as discrete categories. This binaried thinking continued in the work of key social policy authors such as Barbara Bagilhole[51]. Non-binaried identities and bodies were directly erased, and the focus on issues such as women's wages and caring responsibilities, whilst important, are irrelevant to some intersex people, especially those who have been rendered disabled and unable to work due to medical abuse and who have been forcibly sterilised.

It is not just in gender equalities work and scholarship that intersex people are erased. Their invisiblisation is also present in the work of authors addressing LGBT equalities. For instance, Norris and Quilty in an Irish study of 'LGBTQI+' youth homelessness in Ireland indicate that they include intersex research participants[52]. However, there is no evidence of this, or signs of knowledge about key issues for intersex youth, such as experience of non-consensual medical interventions and related trauma and fallout with family[53]. The attachment of the 'I' onto 'LGBT' without specific attention to intersex issues is a broader problem, although there is some good, effective LGBTI policy analysis at an international level[54]. Also, importantly, some intersex people are LGB and/or T[55] but little work has taken place to examine the shared equality policy agendas with endosex LGBT people. Overall, there is a need for more scholarly work on intersex policy making, as well as applied policy interventions.

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[50] Morland, I. (2009). What can queer theory do for intersex? *GLQ: A Journal of Lesbian and Gay Studies 15*(2), 285-312.

[51] Bagilhole, B. (2009). *Understanding equal opportunities and diversity: The social differentiations and intersections of inequality* (1st ed.). Bristol University Press. https://doi.org/10.2307/j.ctt1t89d53

[52] Norris, M. & Quilty, A. (2021). Unreal, unsheltered, unseen, unrecorded: The multiple invisibilities of LGBTQI+ homeless youth. *Critical Social Policy, 41*(3) 468-490.

[53] Callens, N., Kreukels, B. P. C., & van de Grift, Tim C. (2021). Young voices: Sexual health and transition care needs in adolescents with Intersex/Differences of sex Development—A pilot study. *Journal of Pediatric & Adolescent Gynecology, 34*(2), 176-189.e2. https://doi.org/10.1016/j.jpag.2020.11.001

[54] European Union Agency for Fundamental Rights. (2020). *A long way to go for LGBTI equality*. Publications Office of the European Union. https://data.europa.eu/doi/10.2811/7746

[55] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change*. University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/33535/

5. Poststructural Policy Analysis of Equality, Diversity and Inclusion documents in Ireland and England

To explore the silences and assumptions in social policy around intersex issues, the postgraduate researcher (PGR) from Early Career Project 2 analysed 18 policy documents from different policy sectors in Ireland and England. These sectors included social work, healthcare, education, criminal justice, and employment. Listed below are the documents that were included in the policy analysis:

1. Social Care Ireland (Protection of Children and Vulnerable Adults Policy)
2. National LGBTI+ Inclusion Strategy 2020-2021 (Ireland)
3. Health Information and Quality Authority (Guidance on a Human Rights-based Approach in Health and Social Care Services-Ireland)
4. Department of Health and Social Care England: Equality Objectives 2019-2023
5. First Annual Report on the implementation of the Lesbian Gay Bisexual Transgender Intersex (LGBTI+) National Youth Strategy 2018-2020 (Ireland)
6. Manchester City Council (Equality Objectives 2020 (England)
7. LGBT Health Inequalities in the UK (LGBT Foundation)
8. An Garda Siochána (Equality, Diversity and Inclusion Strategy Statement and Action Plan 2020-2021)
9. British Association of Social Workers Human Rights Policy
10. National Police Chiefs Council, The Honour Based Abuse National Delivery Plan 2018-2021 (England)
11. Better Outcomes, Better Futures (The National Policy Framework for Children and Young People. 2014-2020) (Ireland)
12. Health Service Executive (Looking after your mental health for LGBTI+ people) (Ireland)
13. Department for Education Outcome Delivery Plan: 2021 to 2022 (England)
14. Ireland DEIS Plan 2017 (Delivering Equality of Opportunity in Schools)
15. Government Equalities Office (LGBT Action Plan) (England)
16. Social Work England
17. NHS England response to the specific equality duties of the Equality Act 2010
18. Belongto (LGBT youth organisation Ireland) Annual Report

Bacchian policy analysis is guided by six questions that are listed below[56]:

1. What's the 'problem' (for example, of "problem gamblers", "drug use/abuse", "gender inequality", "domestic violence", "global warming", "sexual harassment", etc.) represented to be in a specific policy or policy proposal?
2. What presuppositions or assumptions underpin this representation of the 'problem'?

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[56] Bacchi, C. L., & Goodwin, S. (2016). *Poststructural policy analysis: A guide to practice*. http://doi.org/10.1057/978-1-137-52546-8_1

3. How has this representation of the ‘problem’ come about?
4. What is left unproblematic in this problem representation? Where are the silences? Can the “problem” be thought about differently?
5. What effects are produced by this representation of the “problem”?
6. How/where has this representation of the “problem” been produced, disseminated, and defended? How has it been (or could it be) questioned, disrupted, and replaced?

Based on an analysis of the policy documents using Bacchi’s WPR approach, the findings confirmed that intersex erasure is endemic across policy sectors. Intersex erasure is defined as the collusion between government actors and the medical establishment to reinforce the gender binary by minimising the occurrence of intersex variations through surgical and hormonal interventions. The basis of intersex erasure in law in England stems from the absence of protection based on sex characteristics in the Equality Act 2010[57]. The Equality Act recognises characteristics such as age, gender identity, race, religion and disability but neglects variations of sex characteristics. The Equal Status Acts 2000-2018[58] in Ireland is comparable to the Equality Act in England and includes similar protected categories like those in England, with special recognition of the Traveller community. Like the Equality Act, the Equal Status Acts do not cover sex characteristics.

Below is a summary of findings by sector documenting intersex erasure:

Government

Both Irish and English governments issued separate documents detailing their plans to support the LGBT communities in each context. In Ireland, they issued the “National LGBTI+ Inclusion Strategy 2020-2021” which lacked concrete understanding of intersex issues. Furthermore, intersex was understood in the context of medicalisation that sought to develop clinical guidelines around intersex treatment. In England, the Government Equalities Office issued the *LGBT Action Plan* which recognised sex characteristics but neglected to address how intersex people are impacted by bullying and harassment, issues that were acknowledged for LGBT people. Another equalities document in England was the “Manchester City Council Equality Objectives 2020” which tracked the implementation of equality measures in marginalised communities based on the Equality Act. However, because sex characteristics are not included in the Equality Act, Manchester City Council does not have data on intersex populations.

Criminal Justice System

In Ireland, the criminal justice system is neither tracking intersex nor transgender prisoners[59]. An Garda Siochána, Ireland’s police force, released their EDI statement and called for policy that recognises different gender identities and expressions. However, their statement does not account for people with sex characteristics and is questionable considering that the Irish penal system does not have explicit policy around transgender and intersex prisoners. In England, the National Police Chiefs Council (NPCC) drafted an action plan which was a

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[57] Government Equalities Office & Equality and Human Rights Commission. (2015, June 16). *Equality Act 2010: Guidance*. https://www.gov.uk/guidance/equality-act-2010-guidance

[58] Irish Human Rights and Equality Commission. *Equal Status Acts*. https://www.ihrec.ie/guides-and-tools/human-rights-and-equality-in-the-provision-of-good-and-services/what-does-the-law-say/equal-status-acts/#:~:text=The%20Equal%20Status%20Acts%202000,membership%20of%20the%20Traveller%20community

[59] Carr, N., McAlister, S., & Servisier, T. (2016). *Out on the inside: The rights, experiences and needs of LGBT people in prison*. Irish Penal Reform Trust.

collaboration between multiple agencies including the NHS, the Department for Education and the Department of Health to address female genital mutilation. Female genital mutilation or cutting (FGM/C) is described as procedures that attempt to remove all or part of the female genitalia including the clitoris and labia[60]. While the action plan attempts to investigate and prosecute cases related to FGM/C, genital mutilation of intersex children is not considered since it takes place in Western medical settings.

Healthcare

Focusing on the healthcare sector, a pivotal domain for intersex EDI, it becomes imperative to implement measures preventing irreversible non-consensual medical interventions. These safeguards could be incorporated into policy documents at the EU Member State level. Simultaneously, there is a critical need for appropriate healthcare provision for intersex individuals across all age groups[61]. This necessity can be addressed by specifying relevant areas of healthcare in policy documents and more broadly. For instance, the existing Irish Health Service Executive document, "Looking after your mental health for LGBTI+ people," assumes commonality in mental health issues among LGBTI+ individuals, primarily focusing on themes like coming out, isolation, harassment, bullying, loss of a partner or spouse, and relationships. While some aspects may apply to intersex individuals, the document lacks explicit acknowledgement of intersex issues. This deficiency could be addressed by introducing directives for developing therapeutic provisions tailored to traumatised intersex individuals[62] and recognising specific challenges they often encounter, such as relationship rejection and intimacy difficulties[63].

Education

To enhance equality, diversity, and inclusion (EDI) for intersex individuals, various sectors like education can undergo modifications. This may encompass providing diversity training for professionals and educational programs for families[64]. It also includes addressing the needs of the intersex population within specific sectors such as education. For example, the Ireland DEIS Plan 2017, titled "Delivering Equality of Opportunity in Schools," addresses the impact of disadvantage on education. A revision of this plan could acknowledge that intersex pupils encounter barriers such as interrupted education due to repeated medical interventions, experiences of medical abuse and related trauma, and stigmatisation and bullying, as well as secrecy, shaming, and isolation[65]. A similar plan was introduced by the Department for Education in England that outlined steps to address disparities among children who come from marginalised and vulnerable populations. However, intersex children are a vulnerable population whose needs are not being addressed in English educational institutions.

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[60] Jones, M. (2017). Intersex Genital Mutilation – A Western Version of fgm. *The International Journal of Children's Rights*, *25*(2), 396-411. https://doi.org/10.1163/15718182-02502008

[61] Crocetti, D., Monro, S., Vecchietti, V. and Yeadon-Lee, T. (2020) 'Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health', *Culture, Health and Sexuality,* November https://doi.org/10.1080/13691058.2020.1825815

[62] See Ferrara, M. & Casper, M.J. (2018). *Genital Alteration and Intersex: A Critical Analysis*. *Current Sexual Health Reports,* 10, 1-6.

[63] Frank, S.E. (2018). Intersex and Intimacy: Presenting Concerns About Dating and Intimate Relationships. *Sexuality and Culture,* 22: 127-147. https://doi.org/10.1007/s12119-017-9456-4

[64] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change*. University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/33535/

[65] See Henningham, M. & Jones, T. (2021). Intersex Students, Sex-Based Relational Learning and Isolation. *Sex Education 21*(5), 600-613. https://doi.org/10.1080/14681811.2021.1873123

Social Work

Although social work is a policy sector that directly impacts people with intersex variations, EDI initiatives have not been developed in this area. In England, the Department of Health and Social Care issued their "Equality Objectives 2019-2023" but did not factor in young or older intersex people. This is key because as mentioned elsewhere in this report, some of the ageing concerns that directly impact older intersex people include disability, safety in retirement homes, homophobia, transphobia or interphobia from peers, isolation and financial instability[66]. Because the Equality Act in England underpins EDI work, policies introduced will be deficient in protections for intersex people. For example, Social Work England found that discrimination such as bullying and harassment persists despite the implementation of the Equality Act[67]. Social Care Ireland (SCI) drafted the "Protection of Children and Vulnerable Adults Policy" which outlined how these groups are at particular risk of violence in institutional settings[68]. While there are provisions in this policy such as consent for photography which might be useful to intersex children and adults, more work is needed to understand intersex populations as vulnerable.

LGBT Charities

In the context of EDI work, charities can provide the space to implement equality and diversity measures. As part of the policy analysis exercise, Belong To and the LGBT Foundation were chosen since they represent two well-established LGBT charities in Ireland and England. As indicated earlier in this report, LGBT organisations have sometimes included intersex as part of the LGBT acronym, but intersex issues are often ignored or misunderstood. During the COVID-19 pandemic, Belong To released their annual report which documented the impact of COVID on LGBTI+ youth in Ireland but did not address how young intersex people were mentally coping during the pandemic. In England, the LGBT Foundation collects data related to health disparities in the LGBT community in England. In their report, "LGBT Health Inequalities in the UK", intersex was not mentioned except in the glossary which reinforces the erasure of intersex people in the LGBT community. EDI initiatives in LGBT charities that mention intersex without understanding the complex health and social needs of intersex communities contribute to intersex erasure and undermine the efficacy of advocacy for intersex populations.

Cross-sectoral analysis of policy sectors has revealed the extent to which intersex has been erased in policy documents. To deliver effective equalities legislation, it is imperative to understand the silences and erasures that Bacchian policy analysis offers. Other areas of EDI policy analysis also usually overlook intersex people, notably disability equalities and children's equalities, which are more broadly underdeveloped in the equality and diversity policy literature. Thus, whilst key aspects of equality, diversity and inclusion policy work, such as social justice, tackling discrimination, and assembling legal and policy infrastructures to ensure that these are implemented are highly relevant to intersex people, they are not realised or even visible. This is due to a range of factors including sex/gender binarism and

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[66] see Berry, A & Monro, S. (2022). Ageing in obscurity: A critical literature review regarding older intersex people. *Sexual and Reproductive Health Matters, 30*(1), 2136027-2136027. https://doi.org/10.1080/26410397.2022.2136027

[67] Social Work England. (2021, February 4). *Our Statement of Intent on Equality, Diversity and Inclusion*. Social Work England. https://www.socialworkengland.org.uk/about/publications/statement-of-intent-on-equality-diversity-and-inclusion/

[68] Social Care Ireland. (2022). *Protection of Children and Vulnerable Adults Policy*. https://socialcareireland.ie/wp-content/uploads/2022/08/SCI-Child-Protection-Policy-2022.pdf

endosexism, the ongoing pathologisation of intersex[69] and the lack of substantial disruption to date of endosexism by protest groups. There is also an underlying key issue of nomenclature at play here: the term 'gender' is generally used in equalities discourse, which elides (biological) sex, so that either sex diversities are erased, or intersex people, where they are included, are mistakenly wrapped into the categories of 'transgender' or 'sexual orientation'[70].

6. Cross-Sectoral recommendations for policymakers in the case studies of Ireland and England

Stakeholder interviews and action learning sets were conducted with 21 key stakeholders from Ireland and England. Action learning sets were developed by Reginald Revans at Manchester University in England to address problems in the workplace[71]. Revans created action learning sets as a way for people to collectively solve problems without the direction of experts and outside facilitators. The following recommendations are in the areas of healthcare, employment, social work, and government and were generated from research participants and intersex organisations in both contexts.

Healthcare

- National healthcare systems (i.e. Health Service Executive in Ireland and NHS England) should provide clear, direct information and early testing for intersex variations like Mayer-Rokitansky-Küster-Hauser (MRKH) Syndrome and Klinefelter's Syndrome that are often detected during adolescence.
- Provide training and awareness raising for GPs and medical providers to recognise, diagnose and treat medical conditions that arise from certain intersex variations such as salt wasting in patients with Congenital Adrenal Hyperplasia (CAH) or osteopenia/osteoporosis in people with Androgen Insensitivity Syndrome (AIS) or streak gonads.
- Healthcare systems should seek advice from patient advocates and key stakeholders about understanding intersex variations.

Employment

- EU member states should allocate funding through research to understand the needs of intersex workers.
- Organisations should develop guidelines for supporting intersex people in the workplace. While organisations such as UNISON[72] and the International Labour

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[69] Carpenter, M. (2019). Joint Statement on the International Classification of Diseases 11. Intersex Human Rights Australia. https://ihra.org.au/35299/joint-statement-icd-11/

[70] See for example Norris, M. & Quilty, A. (2021). Unreal, unsheltered, unseen, unrecorded: The multiple invisibilities of LGBTQI+ homeless youth. *Critical Social Policy, 41*(3) 468-490.

[71] Revans, R. (2017). ABC of Action Learning. Taylor and Francis. https://doi.org/10.4324/9781315263533

[72] UNISON. (2020). Bargaining for intersex equality. https://www.unison.org.uk/content/uploads/2021/02/bargaining-for-intersex-equality-Mar-2020.doc

Organization[73] have created guidelines for the welfare of intersex workers, they only account for a small percentage of intersex workers globally.
- EU member states need to implement measures to address discrimination based on sex characteristics. Intersex workers encounter homophobia and transphobia based on perceived differences in sex characteristics. As a result, intersex workers contend with bullying, harassment, and underemployment[74].

Social Work

- Develop training for social workers on the needs of young intersex people, supporting intersex people as adoptive parents, and understanding how medical trauma impacts intersex clients.
- Coordinate statements of support from regulatory bodies within social work.
- Educate carers and foster parents about the needs and health concerns of intersex children and older adults.

Government

- Fund intersex organisations to carry out policy initiatives. Equality Network is an LGBTI charity in Scotland that receives funding from the government to further intersex equalities work and legislation. This stands in contrast to the lack of funding that intersex organisations receive globally[75].
- Draft legislation that is intersex-inclusive and does not reinforce the pathologisation of intersex variations.
- The departments of health in respective states should outline support for intersex people across the lifespan and consider intersex issues in social care planning.

This section of the report has provided some in-depth analysis of the specific situations regarding intersex people, policy making and policy implementation in Ireland and England. Lessons may be drawn out for EU Member States beyond Ireland, but it is important to remember that each Member State has many specificities. The report now moves on to provide a synthesis of the findings across the INIA project.

7. The INIA project policy findings synthesis

The INIA project contributed to knowledge and recommendations in several sectors regarding intersex people. The Older People's guidelines are based on findings from project 1 (Older intersex people in Europe) and the Human rights recommendations are based on the

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[73] Morrison, K. & International Labour Organization. (2022). Inclusion of lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ+) persons in the world of work: a learning guide. ILO. https://policycommons.net/artifacts/3357241/inclusion-of-lesbian-gay-bisexual-transgender-intersex-and-queer-lgbtiq-persons-in-the-world-of-work/

[74] Agius, S. (2017). Human rights and intersex people. Council of Europe Commissioner for Human Rights. https://rm.coe.int/16806da5d4

[75] Howe, E., Frazer, S., Dumont, M. and Zomorodi, G. (2017). The State of Intersex Organizing: Understanding the Needs and Priorities of a Growing but Under-Resourced Movement (2nd Edition). American Jewish World Service, Astraea Lesbian Foundation for Justice and Global Action for Trans Equality. https://gate.ngo/the-state-of-intersex-organizing-report-2017/

findings from project 10 (The rights to bodily integrity, autonomy and self-determination - Demands and strategies of international and regional intersex activist networks and human rights bodies).

Synthesis of findings from the INIA projects was carried out in 2023. This was based on Qualitative fieldwork with intersex people and parents/carers: 176 participants (145 interviews and 31 people within 7 focus groups). The interviews and focus groups were done with the different profiles defined in the project: Intersex people; different service providers (such as health care professionals, social workers, and charity workers); intersex advocates and activists; policymakers; academics and experts; and family members of intersex people. Qualitative research was also conducted with practitioners (focus groups; interviews, ALS) was also conducted; this included 60 people (33 interviews and 27 participants in focus groups). Different profiles included service providers (such as health care professionals, social workers, and charity workers); policymakers; and academics and experts. Depending on each ESR project, the analysis of the empirical data has been done using different methods: thematic analysis, hermeneutical analysis, and critical narrative analysis. Lastly, a survey of healthcare practitioners and peer educators took place across Europe using Qualtrix, with over 300 responses, which were analysed using descriptive and inferential methods.

Education recommendations:

It is probable that there are students with intersex variations in every school. However, they are also highly likely to be unacknowledged with the consequence that their specific needs are overlooked within the school community. People with intersex variations experience psychological and social issues of which schools are often unaware.

The lived experiences that people with intersex variations shared with INIA researchers identify different issues arising in the school context. These can include:

- Increased rates of absenteeism and dropout
- Discrimination and bullying
- Lack of knowledgeable health and counselling services
- Negative experiences within toilets bathrooms, and changing facilities

More often than not, intersex variations are entirely excluded from education within both the formal and informal curricula. Where they are addressed, they are reduced to the context of medical pathology, mythology, or LGBT issues. This leads to the social exclusion of students with intersex variations in the school context.

Things to consider:

- Many people with intersex variations identify school as the start of lifelong experiences of exclusion.

- The medical and psychological trauma that students with intersex variations may carry is not acknowledged by many schools.

- Students with intersex variations may experience prolonged, and often repeated, absences due to medical interventions, which may negatively impact their well-being on many levels, including physical and psychological health; academic performance; feelings of belonging; and the ability to form and sustain friendships.

● Students with intersex variations may actively avoid engaging in subjects because they are uncomfortable with attention being drawn to their bodies in spaces such as sports and changing facilities.

● Many students with intersex variations face bullying and exclusion from peer groups at school. This may be amplified once their intersex variation becomes known due to the lack of awareness and acceptance of intersex variations.

● Students with intersex variations may not recognise themselves, or their experiences, in curricula. Intersex variations are often not covered in human biology courses, nor are they covered in other subjects. A strict binary understanding of sex, and a conflation of sex and gender, contribute to the general confusion on this topic.

● The use of outdated, pathologising, and incorrect terminology (e.g., 'hermaphrodite', 'DSD') or confusing intersex with 'trans' or 'non-binary' when discussing intersex variations is still prevalent and is often the only reference students with intersex variations will find about themselves in any literature.

● Students with some intersex variations may have specific learning and/or physical needs, for example, dyslexia or fatigue, which must be met to support their optimal learning.

Recommendations from the findings synthesis:

- ✓ Raise awareness and acknowledge the existence of people with intersex variations in the classroom, regardless of whether there is a known student with an intersex variation amongst the cohort.
- ✓ Be sensitive to the health and well-being of students with intersex variations. Be aware of potential experiences of trauma, and champion friendly and inclusive spaces.
- ✓ Train education and support staff on the issues and needs of people with intersex variations.
- ✓ Review whether your anti-bullying and harassment policies address the needs of students with intersex variations.
- ✓ Create inclusive policies that consider the needs of students with intersex variations, such as gender-neutral uniform policies.
- ✓ Provide comprehensive sex education that not only includes information about intersex variations but also explores social aspects, such as relationships with peers and with their own bodies. This also encompasses discussions around bodily autonomy, consent, and personal boundaries.

Key recommendations from the literature:

- When creating policy around sex education, follow the UNESCO definition of Compulsory Sex Education (CSE). This is defined as a curriculum-based process of teaching and learning about the cognitive, emotional, physical and social aspects of sexuality. Programmes should include biological aspects of sex and disease prevention as well as the social, emotional, interpersonal, and positive aspects of sexuality[76].

- Provide teacher training on sex education and intersex issues consistently at pre-service levels and make it more accessible to teachers already in the workforce. This training should be based on norm-critical approaches that question normative thinking around bodies and sexuality and combat stigmatisation and pathologisation[77] instead of a liberal approach to sex education focused on giving information[78].
- Both equality planning and anti-violence/anti-bullying programmes should include considerations regarding sex, gender, sexuality, and body diversity, including intersex traits and variations of sex characteristics to prevent bullying, discrimination, and violence towards intersex students[79].
- Create regulations to allow students, including some intersex students, flexibility to wear a uniform that matches their identity and to access suitable toilets based on their gender self-identification. School spaces and activities should be transformed so that sex and gender binary divisions are not the only option — or an option at all — in schools[80].
- Facilitate funding and distribution for research in the field of education on topics regarding intersex traits and variations of sex characteristics[81].

Human rights for legal policy makers

Intersex genital surgery is the main concern by human rights activists and has been considered as a practice that contradicts many current human rights standards.

International human rights monitoring bodies within the United Nations have highlighted some aspects that contradict international human rights norms, for example that these surgeries and treatments:

(a) are medically unnecessary

(b) are non-urgent

(c) are carried out too early or mostly on children

(d) are intended to decide or assign sex

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[76] Ketting, E., Brockschmidt, L. & Ivanova, O. (2021). Investigating the ‘C’ in CSE: implementation and effectiveness of comprehensive sexuality education in the WHO European region. *Sex Education, 21*(2), 133-147. https://doi.org/10.1080/14681811.2020.1766435

[77] Keating, A., & Lehtonen, J. (2022). *Intersex traits and variations of sex characteristics in education: a Finnish context*. University of Dublin. https://doras.dcu.ie/26683/

[78] Lundberg, T., Roen, K., Kraft, C., & Hegarty, P. (2021). How young people talk about their variations in sex characteristics: making the topic of intersex talkable via sex education. *Sex Education*, 21(5), 552–567. **https://doi.org/10.1080/14681811.2021.1911796**

[79] Keating, A., & Lehtonen, J. (2022). *Intersex traits and variations of sex characteristics in education: a Finnish context*. University of Dublin. https://doras.dcu.ie/26683/

[80] Keating, A., & Lehtonen, J. (2022). *Intersex traits and variations of sex characteristics in education: a Finnish context*. University of Dublin. https://doras.dcu.ie/26683/

[81] Keating, A., & Lehtonen, J. (2022). *Intersex traits and variations of sex characteristics in education: a Finnish context*. University of Dublin. https://doras.dcu.ie/26683/

(e) are irreversible or have long-lasting consequences

(f) entail pain or suffering

(g) are carried out without the person's informed consent

Unconsented medical treatments that are often harmful, including surgeries, are carried upon intersex persons all over the world. Regarding the European region, according to the European Union Agency for Fundamental Rights (FRA),2 'normalisation' surgeries are performed out on intersex children in at least 21 member states of the European Union (EU). Among the member states of the EU and the Council of Europe (CoE), by October 2023, only six countries (Malta, Portugal, Iceland, Germany, Greece and Spain) have legislation that provides some form of protection against these types of interventions during early childhood.

Legal and Human Rights policy recommendations

- ✓ Listen to intersex persons. The research findings suggest that intersex persons and civil society groups have a hard time making their concerns heard when they engage with local politicians and with law and policymakers.
- ✓ Meet with intersex persons. Intersex issues might be a complicated topic to understand, therefore it is recommended that law and policymakers meet and listen to intersex persons directly to understand their needs and demands. Consider also that different contexts may bring different situations that need to be addressed locally. Believe intersex people. Even when intersex persons gain access to law and policymakers their claims are often dismissed as non-important or more value is given to medical views that often are pathologising and in conflict with intersex persons' concerns.
- ✓ When working on law or policy, consider holding separate meetings for health practitioners and intersex advocates. If meetings are taken place jointly, warn intersex persons about the presence of doctors as some might find it triggering (and they might choose not to participate).
- ✓ Be aware of the pathologisation of intersex bodies. A great number of medical professionals and medical literature still has pathologising views of intersex bodies. The ICD-11 for example classifies most intersex bodily variations as 'Disorders of Sex Development (DSD).' Biased medical knowledge founded upon the idea of 'fixing' or 'normalising' bodies tends to see intersex variations as a problem, however most of these bodily variations are not harmful or life-threatening, only in a small number of cases interventions on minors are needed for life-saving purposes.
- ✓ Many intersex persons consider that viewing their bodies as 'disordered' contributes to the idea that they need a 'fix' leading to harmful and invasive medical treatments, including extensive hormonal therapy and/or genital surgery
- ✓ Take action. Design and implement policies and legislation to guarantee intersex persons' human rights. Intersex persons' rights are the same as everyone else's, for example the right to life, health, bodily integrity, etc. However, harmful practices on intersex bodies have been normalised, socially and medically accepted and turned into systemic and institutionalised forms of rights violations. Specific laws and policies may be necessary to counter this situation.

- ✓ Support access to information about being intersex and intersex persons' experiences and human rights. The invisibility of intersex people's issues and realities supports a climate of secrecy, stigma and/or ignorance. This may harm intersex persons' life experiences, as they often need to justify their realities and 'come out' to different persons when needing access to public services, for example, in school, to access healthcare or at work. Promoting a culture of basic information and education about bodily variations and diverse sex characteristics is a first step towards creating a more inclusive and accepting society and can make it easier for intersex persons to speak about their experiences when they want to do so.
- ✓ End harmful medical practices performed upon intersex persons. Governments have a responsibility when harmful medical practices are allowed to be carried out rampantly and without regulation or safeguards, this is true in the case of intersex persons as it is for everyone else. Treatments and surgeries that are invasive, not urgent, have long-time consequences, and may inflict pain or prolonged medical interventions should only be conducted with the patient's full, personal, prior and informed consent.
- ✓ Law and policymakers should take action to end and prohibit harmful medical practices (e.g, surgeries, neovaginal dilations, or hormonal treatments) that are performed without the intervened person's consent if they are too young to understand and the interventions are not urgent or medically necessary to save the person's life.
- ✓ In cases where there is doubt about the necessity of treatments (e.g., to improve health or bodily functions)governments should develop appropriate and transparent health protocols to determine this necessity and make sure these treatments are in line with non-pathologising ethical principles and human rights standards (in particular, autonomy, bodily integrity, and children's rights).
- ✓ Governments must make sure these decisions are reviewed by independent, balanced and multidisciplinary bodies that take into consideration the human rights of the intervened person and do a fair balance between the necessity of the intervention and the risks, and possible consequences of the same.
- ✓ Take measures to guarantee intersex persons' access to healthcare services. Like everyone intersex persons have healthcare needs. Law and policymakers should take steps to secure the right of intersex persons to access healthcare in conditions that respects their human rights, especially their right to informed consent throughout their life.
- ✓ Likewise, governments should ensure the services of high-quality specialist and individualised healthcare for all intersex persons. Governments should invest in training and professional development for health professionals including knowledge about bodily, sex and gender diversities.
- ✓ The right to medical information should be guaranteed. This includes the right of parents and/or guardians to have the full and comprehensible information about what treatments are or have been conducted on their child, plans for future treatments, risks, necessity, and alternatives of such, including the possibility of deferring treatment until an older age where the person can consent.
- ✓ Persons' rights to have access to their medical records should be guaranteed. In the cases of intersex persons, it is recommended that medical records be as detailed as possible and stored for the longest time available, giving the opportunity for the person to request such information in adolescence or adulthood.
- ✓ Support the renumeration of the active engagement of civil society actors. Sometimes intersex persons with lived experience provide services, like advice and counselling

for intersex persons and their families. They may also be consulted in the design and development of legislation and public policies. Supporting their work financially helps keep these services available over time.

- ✓ Take the necessary measures to repair the damage made. New provisions, policies and legislations can benefit intersex persons from the moment they are implemented. However, many already have suffered from surgeries or medical treatments performed in the past. Governments need to take steps to provide reparations and redress to those who already suffered because of these harmful medical practices

Older people recommendations

Key recommendations for policymakers and practitioners working with older people in different sectors are:

- ✓ All care providers should be aware that intersex people and those with variations of sex characteristics (VSCs) exist and they should not assume that a client or patient is not intersex. Some people with VSCs may identify with the medical term for their variation and may not have heard of the term ‘intersex’, so there is a need for care providers to familiarise themselves with different VSCs.
- ✓ Older intersex people may have specific healthcare needs or other needs specific to being intersex, for example, mental health needs due to having suffered from harmful medical interventions. A trauma-informed approach is useful.
- ✓ Older intersex people have often had bad experiences in medical settings due to discrimination or harmful interventions. They may therefore avoid seeking help even if they need it. Care providers should be aware of this and find ways to support their older clients/patients, whether that is advocating for them, providing encouragement, or tackling discrimination in healthcare settings.
- ✓ As intersex people get older, they are likely to need a range of health interventions, some of which will be specific to their VSC or to supporting them with healthcare needs caused by unnecessary interventions carried out when they were children (for example specialist hormonal replacement therapy due to gonads having been removed). Appropriate care by specialists is extremely important and needs resourcing.
- ✓ Older intersex people have valid worries about experiencing discrimination when they can no longer live independently, for example, fears about their genitals being seen by carers. Carers need to be highly sensitive, respecting people’s privacy but providing reassurance about bodily differences, and finding ways to convey acceptance and support.
- ✓ Some older intersex people experience harassment, shaming, or bullying due to appearing to not fit gender norms, or when they disclose having a VSC. There have also been instances of severe discrimination by care providers (e.g. care refusal) and of the use of intersex people for training purposes without their consent. There is a pressing need to develop and implement measures to stop the victimisation of older intersex people and discrimination against them, in all sectors.
- ✓ There is a strong need for resourcing the development and provision of education across sectors for front-line staff and others who may come into contact with older intersex people so that they can support them properly. As these resources need to be informed by the patient group themselves, developmental and capacity-building

work is needed, as the voluntary sector for people with VSCs is very thin and overstretched.

- ✓ Existing Equality, Diversity and Inclusion policies and mechanisms can be used to help older intersex people, for example by including new training modules or policies.
- ✓ It is important that policymakers and practitioners are aware that some intersex people are LGBT, and some are heterosexual[82]. Support for LGBT older people more generally is necessary, but if intersex is included in the LGBT acronym, intersex-specific measures are needed (such as recognising the damage that medical interventions may have caused).
- ✓ Practitioners who work with older intersex people may themselves need support, as these people have often experienced a lot of trauma. They may be especially vulnerable, for example having no family due to estrangement and/or an inability to have children (sometimes caused by unnecessary medical interventions). Good supervision and support for carers is needed.

Indicative cross-sectoral policy recommendations

According to research provided by the INIA project, intersex people and people with VSCs have been erased from policy frameworks and interventions at the most basic level - what is considered as a relevant policy issue. Social policies have assumed that there are only people with traditionally male or female bodies, and that only male and female genders exist. This means that VSC people may be overlooked by both mainstream and gender-specific policy interventions.

Research by the INIA team and others shows that appropriate health policies are crucial for supporting people with VSCs. However, policy work across other sectors is also central to supporting and including people with VSCs, and to tackling the discriminations they face. At present, insufficient provision exists to support people with VSCs in sectors including education, safety and protection from hate crimes, employment, sport and leisure, social work, and welfare benefits. The INIA research found that there is not enough policy work about people with VSCs across the life course, with a particular lack of support for adult and older people with VSCs, and those with intersectional marginalities such as disabilities.

The research showed a pressing need for resourcing, education, awareness building, and training of policy actors and sector-level practitioners to enable them to support people with VSC. Effective policies to support VSC equality, diversity and inclusion are being developed at transnational and in some cases national levels but implementation mechanisms are required across different sectors. These could include for example sector-specific impact assessments and monitoring of interventions. It is crucial for policymakers to work together with people with lived experience of VSCs. Robust consultation and partnership mechanisms are needed, and resources are required to support this.

Specific issues:

- ➢ People with VSCs experience high levels of discrimination different social policy sectors. Outside of medical contexts, their existence is often overlooked.

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[82] Russell, C., Amoroso, I., Hugo, J., Kromminga, I. (2023). *Diving into the FRA LGBTI II Survey Data: Intersex Briefing*. https://www.ilga-europe.org/files/uploads/2023/05/FRA-Intersections-Report-Intersex.pdf

- ➢ Within medical settings, the practice of medically unnecessary interventions has policy implications (e.g., on peoples' ability to contribute to the labour market) which are often ignored, whilst appropriate care is often lacking.
- ➢ VSC people's issues are frequently unaddressed in policy frameworks within EU member states, meaning that their needs are not met via equality, diversity, and inclusion interventions.
- ➢ Within different policy sectors, there is usually an absence of measures to address the specific needs and issues of people with VSCs.
- ➢ Where VSC people are included in policies, it is often alongside LGBT people. Whilst this can be useful, and some people with VSCs are also LGBT, it carries the risk that VSC people's specific issues remain unaddressed.
- ➢ Many people with VSCs do not identify as intersex, as having a VSC, or with groups such as LGBT people. There is a risk that they get overlooked by policy interventions if these are not inclusive.

Recommendations:

- ✓ Awareness raising, training and support for policy makers and those who implement social policies, across all sectors.
- ✓ Review of all policies at supranational, national, regional, and local levels to ensure that people with VSCs are included and that measures are present to tackle discrimination.
- ✓ Resourcing and capacity building across key sectors including healthcare, education, social work, public safety, and employment, to ensure that the specific needs of people with VSCs are met.
- ✓ Policy work to address the needs of adults, including older people, is particularly important due to insufficient work to date.
- ✓ Increased capacity-building and training 2of social workers, psychologists, educators and other front-line practitioners to enable better support to families of those with children with VSCs, and people with VSCs, across the life course.
- ✓ Care should be taken to include variation specific people (those who identify with a particular variation or condition) and those who identify as intersex. It is necessary for policy makers to be aware of the wide differences across people with VSCs.
- ✓ Support and renumeration is needed for the active engagement of those with lived experience of VSC in the process of policy making and implementation.

8. Conclusion

This report has provided an overview of literature relevant to policy development concerning intersex people in Europe. It has synthesised and presented key policy-relevant findings from the INIA project across several sectors, whilst highlighting the way that policy work in this field is very underdeveloped in many ways. The report also provided a substantive analysis of policy erasures and policy issues from the case study project based on Ireland and England. The conclusion of the report now provides some thoughts about overall policy approaches, as relevant to intersex policy making.

One approach to advancing the equality of for intersex people in policy work involves adopting a top-down strategy and Equality, Diversity and Inclusion (EDI) approaches. An example of a top-down strategy regarding EDI is provided by the European Commission 2022 publication 'Guidelines for Strategies and Action Plans to Enhance LGBTIQ Equality'[83]. These guidelines support practical interventions to protect the rights of LGBTIQ people, taking into account the diverse state and legal infrastructures of EU Member States. They recommend measures to identify current situations and challenges to LGBTIQ equality to inform evidence-based policy development, setting priorities to promote LGBTIQ awareness and equality, ensure legal protections and their implementation, good governance (for example transparent leadership and coordination of interventions and the engagement of civil society actors), and evaluation mechanisms to ensure that equality work is taking place and is effective. Whilst this document does not address many of the specific challenges facing intersex people, it notes that there is a need to focus in particular on the experiences of intersex people concerning poverty, employment, social exclusion, and (more broadly) intersectional discrimination. It provides a very useful map of strategic mechanisms that can be used to support intersex-related policy reform.

Top-down policy reform to support intersex people's wellbeing and equality could further include conducting a thorough analysis of organisational structures, and examining how endosexism, interphobia, and related issues like gender binarism and homophobia operate within institutions. It also entails proactively devising strategies to address these issues. As previously mentioned, there are fundamental challenges, including the pathologisation of intersexuality and the discursive marginalisation of intersex individuals by framing variations in physical sex characteristics as matters of gender and sexual identity. The notable absence of impactful intersex EDI initiatives allows the continued relegation of sex variations to the medical domain. Some healthcare professionals, particularly those specialising in the field and possibly invested in the perpetuation of non-consensual irreversible interventions on minors, may contribute to this trend[84].

Reconceptualising intersex as primarily an EDI concern, with the inclusion of the need for appropriate healthcare as one component, could serve as one foundation for policy and practice reforms, alongside healthcare reform and the implementation of human rights directives. Employing standard EDI tools, such as consultation frameworks that incorporate the perspectives of service users[85], is crucial, especially for intersex individuals who have historically been excluded from service planning and delivery. Existing intersex organisations play a leading role in policy reform and should receive support and capacity-building as key stakeholders[86].

To mainstream intersex EDI across various sectors, including education, employment, refugee services, policing, sport, and the media, specialised guidance and training can be integrated

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[83] European Commission. (2022). *Guidelines for Strategies and Action Plans to Enhance LGBTIQ Equality: LGBTIQ Equality Subgroup*. https://commission.europa.eu/system/files/2022-09/guidelines_for_strategies_and_action_plans_to_enhance_lgbtiq_equality_2022final16_05.pdf

[84] Crocetti, D., Monro, S., Vecchietti, V., & Yeadon-Lee, T. (2021). Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health. *Culture, health & sexuality*, *23*(4), 500–515. https://doi.org/10.1080/13691058.2020.1825815

[85] Ebuenyi, I. D., Smith, E. M., Munthali, A., Msowoya, S. W., Kafumba, J., Jamali, M. Z., & MacLachlan, M. (2021). Exploring equity and inclusion in Malawi's National Disability Mainstreaming Strategy and Implementation Plan. *International journal for equity in health*, *20*(1), 18. https://doi.org/10.1186/s12939-020-01378-y

[86] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change*. University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/33535/

into existing EDI provisions. For a profound shift in cognitive and discursive frameworks surrounding sex characteristic variations, we propose the utilisation of organisational change methods in developing training programs for healthcare professionals and medical policy stakeholders accustomed to operating within the 'DSD' (Disorders of Sex Development)/pathologising and sex-binary frameworks prevalent in medicine over the past 60-70 years in the VCS field[87]. An alternative approach to developing intersex EDI policies involves tailoring support for intersex individuals in a sector-specific manner. A further approach is supporting bottom-up approaches to social policy reform, in particular resourcing intersex-led NGOs, as there are often major deficits in funding and hence capacity amongst these[88]. An example of resourcing intersex-led NGOs has been provided by the Astraea Intersex Human Rights Fund, which provided grants totalling over a half million dollars to 53 intersex organisations globally[89].

Overall, it is important to recognise that implementing intersex EDI initiatives may encounter challenges. For instance, one study found that despite progressive discourses and supportive legislation regarding LGBTQIA+ issues in education, there were still discriminatory discourses and practices in classrooms[90]. The field is fraught with tensions, including conflicts between parents seeking privacy and advocating for early non-consensual irreversible interventions for their children, and intersex NGOs concerned with awareness-raising and reform.[91] Nevertheless, navigating tensions, addressing implementation gaps, and overcoming resistances are inherent aspects of equality work[92]. As with other areas, finding ways forward, such as the development of equality impact assessments and monitoring, will be essential. Whilst some of the issues raised by consideration of intersex and VSCs may be challenging, there is much to be gained by policies that support intersex people and people with VSCs. There is a business case, as people who are able to live free from discrimination are more able to contribute to society and to avoid being a burden on welfare systems. There is also a social justice case, as the continued exclusion causes unnecessary suffering for people with VSCs and their families and communities.

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[87] See Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change*. University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/33535/

[88] See Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change*. University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/33535/

[89] Astraea Lesbian Foundation for Justice. (2021). *Celebrating the Growth and Leadership of Global Intersex Movements*. https://www.astraeafoundation.org/stories/celebrating-the-growth-and-leadership-of-global-intersex-movements/

[90] Sperling, J. (2021). Comprehensive sexual health education and intersex (in)visibility: An ethnographic exploration inside a California high school classroom. *Sex Education, 21*(5), 584-599. https://doi.org/10.1080/14681811.2021.1931834

[91] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change*. University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/33535/

[92] Richardson, D., & Monro, S. (2012). *Sexuality, equality and diversity*. Palgrave Macmillan.