

D5.2.4 Report on systematic explorative review of documents contributed by the international intersex movement, international and regional human rights bodies and recent scientific bibliography

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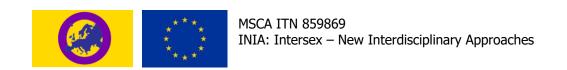
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Report on systematic explorative review of documents contributed by the international intersex movement, international and regional human rights bodies and recent scientific bibliography

1. INTRODUCTION

Intersex is a term used as an umbrella term to encompass people born with innate differences of sex traits such as genital, gonadal, hormonal, or chromosomal characteristics that seemingly challenge binary medical and social conceptions of what the male and female body are expected to look like.

The United Nations Office of the High Commissioner of Human Rights (OHCHR) considers that the term intersex describes: "a wide range of innate bodily variations in sex characteristics. Intersex people are born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns". (1)

In 2006, however, a group of medical practitioners challenged this conceptualization of the term and proposed a shift from "intersex" to the newly created term "Disorders of sex development" (DSD) which has since been used in medical settings to encompass over 40 variations of sex characteristics. The term DSD is defined by "congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical." (2)



Intersex activism is fairly 'young' compared to other forms of activism, for example feminism, or LGBT activism. While people with different variations in their sex characteristics have always existed, research suggests that it wasn't until the late 80's and early 90's that people who identified themselves as 'intersex' started to come together to advocate for political goals. (3–7)

Also, while patient associations, support groups or what I will call here 'patient groups' have also been present for a long time, even before intersex activists, a recent study suggests that these groups often characterized themselves by limiting their scope of actions to a specific diagnosis or set of diagnosis, providing peer support, and advocating for better health care access or treatments. (8) While these can be seen by some as political and human rights claims, this study observes that patient groups often are not particularly interested in engaging politically or 'critically' for systematic or legislative change and tend to reject the label of 'activist.' (8)

A lot of the existing literature on intersex activism and (human) rights claims is focused on the United States, this has to do, perhaps, with the long and well documented history of US trans and intersex activism; the well documented efforts of the Intersex Society of North America, one of the first public and visible organizations in the country, and the published memoirs of its founder Chery Chase, (3) but undeniably it has to do also with the hegemony of the United States, the power and importance of American academia and access to dissemination resources, as well as the privilege that is to have and produce information in English, considered fairly accessible to foreign English speakers and researchers around the globe. (9) This does not mean however that 'intersex activism' was not happening elsewhere or at least one shouldn't assume so. In Europe different political groups started to take on the label of 'intersex activists' as well, with some of the most visible countries being France, Germany and the UK. Intersex activism has also a long history in Australia, New Zealand, and Argentina. (10–12)



2. METHODOLOGY

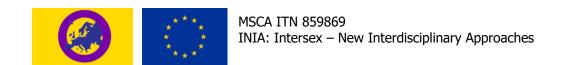
The report consists of three document and literature reviews:

In the first review, I looked for and analyzed the main demands coming from different intersex activist groups present in international and regional declarations and how human rights framings are included in them.

In the second part of the report, I reviewed international and regional declarations or statements and recommendations coming from international human rights monitoring bodies (IHRMBs) and observe how they resonate with the demands from activists, particularly from their region.

In the third part, using a scoping review methodology, I review how scholarship considers human rights regarding intersex people.

In all three reviews I analyzed also how the topic of 'reparations' or access to justice mechanisms is considered within the main demands coming from intersex activists' documents, recommendations from IHRMBs and intersex studies scholarship, this is because in a previous work I encountered that this issue is often less visible as a matter of human rights priorities in literature and activist documents but has been gaining visibility in other fields, for example amongst UN treaty bodies. (13) Each of the subchapters below include a more detailed methodology.



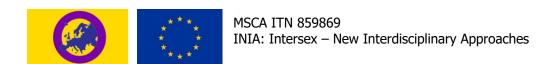
3. RESULTS

3.1. Review of intersex activists' demands

3.1.1. Methodology

As stated above, for the first review I looked for and analyzed the main demands coming from different intersex activist groups present in international and regional declarations and other statements. The review includes a summary of the most relevant themes of each recommendation without reproducing the complete content and order.

I decided to focus on these grand statements because there are plenty of different position statements, public statements or research documents such as reports, factsheets or guides coming from different groups, to the point that is extremely difficult to gather them all. The documents that were selected, were so because they: a) gather different positions from regional or international activists and organizations; b) they present demands summarized in order to make sense to lay people and often law and policy makers and c) they can be understood as the culmination of internal negotiations regarding prioritization of political goals and demands and framing of issues. A total of 7 activist documents were included in the review. The Yogyakarta Principles and Yogyakarta Principles plus 10 were also included as they are relevant pieces of literature inclusive of matters relevant to intersex persons (amongst other groups) and speak directly about international human rights law perspectives.



3.1.2. Summary of activist documents review

3.1.2.1. International documents

3.1.2.1.1. The Malta Declaration

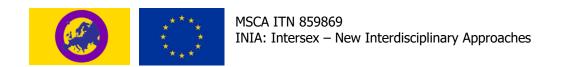
In December 2013, following the Third International Intersex Forum, an event that brought together 34 activists representing 30 intersex organizations from all continents, intersex activists published the Malta Declaration. (14) The Malta Declaration is a document that puts together a list of priority demands in which intersex activists from different places could find common ground.

The main demand of the Malta Declaration is "to put an end to mutilating and 'normalising' [sic] practices such as genital surgeries, psychological and other medical treatments through legislative and other means", as well as to empower intersex people to "make their own decisions affecting own bodily integrity, physical autonomy and self-determination." (14)

Other demands can be classified as: those having to do with stopping other abusive and harmful practices, including medical practices, access to medical records and professional training, those having to do with sex registration and gender recognition; those having to do with cultural awareness, and building safe spaces for intersex people; those having to do with ending discriminatory practices, particularly with regards to family life and sports inclusion and other more specific claims, for instance putting an end to infanticide and killings of intersex people. Of course, all of these claims intertwined often with one another.

There is also one specific claim about reparations.

• To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth. (14)



3.1.2.1.2. The Yogyakarta Principles and Yogyakarta Principles plus 10

The Yogyakarta Principles (15) and the Yogyakarta Principles +10 (16) reflect the doctrines of the most competent publicists, i.e. experts, in both international human rights law and sexual, gender and bodily diversity issues, and so they can be viewed in line with art. 38 of the International Court of Justice Statutes (17) as a source of interpretation of international law. While these principles are not an international instrument of a binding nature, they expand the understanding of States' obligations already enshrined in binding international treaties, in light of the principle of nondiscrimination, with respect to sexual orientation, gender identity, gender expression or sex characteristics. The first set of 29 Principles were developed by human rights experts from all fields, following a meeting in Yogyakarta, Indonesia, in 2006. (15,18,19) More than ten years later in 2017, an additional set of principles known as 'The Yogyakarta Principles plus 10' (YP +10), included the ground of 'sex characteristics' and recognized the rights to bodily integrity, truth and legal recognition. (16,19) According to Morgan Carpenter "The attribute of sex characteristics was identified early as a key development to reflect within the YP plus 10, to address human rights violations based on physical features relating to sex, irrespective of age or agency." (19) Carpenter further affirms that the YP+10 "drew upon developments in domestic law in Malta, other European states and institutions, and the work of the Asia Pacific Forum of National Human Rights Institutions." (19)

The YP+10 include nine new principles, namely the rights to bodily and mental integrity, the right to truth, legal recognition, state protection, freedom from criminalization, protection from poverty, the right to sanitation, enjoyment of information and communication technologies, and cultural diversity.

In terms of reparations, principle 37 of the YP+10, the right to truth, states that:



Every victim of a human rights violation on the basis of sexual orientation, gender identity, gender expression or sex characteristics has the right to know the truth about the facts, circumstances and reasons why the violation occurred. The right to truth includes effective, independent and impartial investigation to establish the facts, and includes all forms of reparation recognised by international law. The right to truth is not subject to statute of limitations and its application must bear in mind its dual nature as an individual right and the right of the society at large to know the truth about past events. (16)¹

To guarantee this right the Yogyakarta Principles plus 10 encompass 9 action points or recommendations, amongst them, to adopt legal provisions to provide redress to victims of violations, to ensure access to remedies that include psychological support and restorative treatments; to ensure people's right to access their medical histories, and medical records; to adopt and implement truth-seeking mechanisms and procedures oriented towards knowing the truth about violations based on sexual orientation, gender identity, gender expression and/or sex characteristics (SOGIESC); to document human rights violations and ensuring communities and society at large are aware and have access to archival information of past human rights violations; to include themes related to rights violations in educational curricula and to recognize the suffering of victims by commemorating rights violations via cultural events. (16)

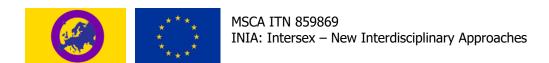
Also, the Yogyakarta Principles already included the right to effective remedies and redress in principle number 28. The principle considers that States shall ensure that:

Every victim of a human rights violation, including of a violation based on sexual orientation or gender identity, has the right to effective, adequate and appropriate remedies. Measures taken for the purpose of providing reparation to, or securing adequate advancement of, persons of diverse sexual orientations and gender identities are integral to the right to effective remedies and redress. (15)

In order to secure the above rights, the Yogyakarta Principles recommend States to establish necessary legal procedures; ensure remedies are implemented in a timely manner; ensure people have access to information about the redress procedures and that

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¹ Bold added.



personal enforcing them are sensitized regarding SOGIESC issues; and that financial aid is provided where needed, amongst other things. (15)

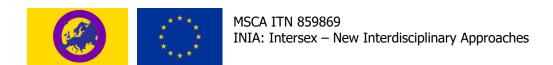
3.1.2.2. European documents

3.1.2.2.1. The Statement of Riga

On October, 8th, 2014 after a meeting that took place in Riga, European organizations working for human rights adopted a statement to "identify objectives and strategies to advocate for the full implementation of human rights and bodily integrity and self-determination for intersex individuals in Europe." (20) Four objectives were established, namely to: challenge the binary definition of sex; antidiscrimination protections for intersex people; to ensure that different stakeholders are instructed on intersex issues from a human rights perspective; and to work towards making non-consensual medical and psychological treatment unlawful. No specific reparation claims or objective were identified. (20)

3.1.2.2.2. The Vienna Statement

In 2017 following the first OII Europe community event in Vienna that gathered 28 intersex persons from 16 Council of Europe member states, the European intersex activist movement issued the Vienna statement with 26 action points oriented towards different stakeholders, for example governments, stakeholders in the field of health care and education, and the media and endosex allies. Amongst the demands there are calls for the ban of IGM and stopping medical treatments to the purpose of modifying the sex characteristics of intersex people until the affected person can consent to them; to protect intersex people from discrimination; to include intersex realities in education efforts, for example school curricula and trainings for public servants and other relevant stakeholders; counselling support, including peer counselling, for intersex people and counselling for their families that is human rights affirming and depathologizing; positive cultural representations of intersex people in the media; claims related to sex and gender



registration; and calls for allies to support intersex movements and not to instrumentalize their claims, amongst other aspects. (21)

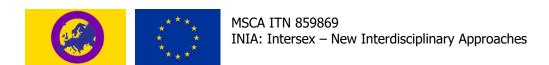
There is one explicit reference to reparations:

• Provide intersex people who endured medically unnecessary or degrading treatment with reparations. (21)

3.1.2.3. Aotearoa/New Zealand and Australian documents

3.1.2.3.1. The Darlington Statement

In 2017, members from the Australia and Aotearoa/New Zealand intersex community organizations and independent advocates, including the Androgen Insensitivity Syndrome Support Group Australia (AISSGA), Intersex Trust Aotearoa New Zealand (ITANZ), Organisation Intersex International Australia (OIIAU, now IHRA, Intersex Human Rights Australia), and individual activists, issued a joint consensus statement. (22) The document sets out the priorities and calls for action under six headings which the document classifies as: a preamble; we acknowledge; human rights and legal reform; health and wellbeing; peer support; allies; and education, awareness and employment. Overall, the document sets out more than 50 demands. Within the above headings calls for action could also be classified as: demand for the prohibition of deferrable medical interventions; legal gender and sex registration claims; nondiscrimination claims; reparation and justice claims; health care and wellbeing claims; claims related to psychosocial and peer support; claims related to ally movements and persons; and claims related to awareness raising and sensitization, particularly in the ambits of education, employment and media. There is one explicit call for government institutions regarding reparations:



We call on governments and institutions to acknowledge and apologise for the
treatment of people born with variations of sex characteristics, and
provide redress and reparation for people born with variations of sex
characteristics who have experienced involuntary or coercive medical
interventions. There must be no time limit on access to redress and reparation.
(22)

3.1.2.4. African documents

3.1.2.4.1. Public Statement by the African Intersex Movement

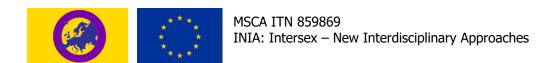
On November 2017, a number of 22 intersex activists from at least 7 African countries gathered in Johannesburg, South Africa and issued a public statement with 16 demands and 6 action points. Aside from the demand to end intersex normalizing surgeries, the top demands call for the prevention of violence against intersex people, for example infanticide; for change in medical practice including the depathologization of intersex variations, access to medical records, trainings for health providers and ending sterilization practices; other demands include those for sex and legal gender registration; awareness raising and education for society at large, for medical professionals involved in health care and for parents as part of antenatal support; antidiscrimination protections including in the field of sports; demands for recognition of harm and for psycho-social and peer support for intersex persons and their families. (23)

No specific claim for reparations was found except as mentioned above claims for recognition of harm.

- To **acknowledge** the suffering and injustice caused to intersex people.
- To **recognise** that medicalization and stigmatisation of intersex people result in significant trauma and mental health concerns. (23)²

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² Bold added.



3.1.2.5. Asian documents

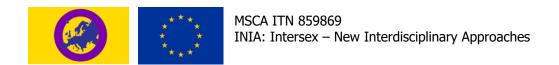
3.1.2.5.1. Statement of the First Asian Intersex Forum

In 2018 intersex activists from the Asia region convened during the First Asian Intersex Forum in Bangkok. The forum brought together intersex activists from at least 10 countries and served as the foundation for Intersex Asia, the first regional network of Asian human rights-based organizations and intersex activists. Following the meeting Intersex Asia published a statement containing 36 demands and 7 calls for action. (24)

Aside from the demand to stop genital surgeries, demands from Asian intersex activists could be categorized as demands for recognition, destignatization and demedicalization; to end abusive medical practices and to provide confidential access to their medical data; demands related to nondiscrimination in all ambits but highlighting employment, family, and sports; demands for psychosocial and peer support; demands for education and awareness raising not just for key stakeholders in the provision of public services but for society at large and human rights education for intersex persons so they can be aware of their rights; sex and legal gender registration claims. There are also some very specific claims related to inheritance; claims related to other different intersectionalities for example intersex people with disabilities and intersex refugees; and demands to protect intersex people from specific forms of violence for example sexual violence, honor killings or infanticide. (24)

In terms of reparations two demands were coded in this area.

- To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth.
- To acknowledge the suffering and injustice caused to intersex people. (24)



3.1.2.6. Latin American documents

3.1.2.6.1. Statement of San José de Costa Rica

The Statement of San José is a document containing a series of 36 demands, that came out after the first Latin American meeting of intersex people that happened in 2018 in San José de Costa Rica. The prologue of the statement calls out historical practices of colonization not just of people's land but bodies as well. The statement also calls for respect of how different intersex groups decide to call themselves in Spanish, Portuguese and other native tongues. While asking for the recognition of the political history of intersex movements in the Latin American region and recognition of geopolitical contexts it also subscribes to the demands of international activists made in the Malta Declaration. (25)

The Statement of San José makes differentiated demands on the basis of political stakeholders, for example, the State, human rights institutions, funders, allied movements, the media, health institutions, family members, and other intersex persons. Aside from the main demand to prohibit unnecessary medical practices carried out without the consent of the of the main person affected, the rest of demands include those concerning health care treatments and intersex medical care practice; those related to sex registration and legal gender identity recognition; claims related to reparations and access to justice. (25) Contrary to the Malta Declaration, the Statement of San José is framed more in the line of petitions rather than demands. Three of the petitions made in the Statement of San José seem to directly speak to reparations and recognition of harm.





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- 5. Guarantee the right of all persons subjected to any practice aimed to modify their sex characteristics to learn the truth about their birth, sex assignment, diagnosis, practices performed on their body and their rationale, as well as the names of those involved in such practices and their follow-up.
- 6. Recognize that pathologizing our bodies has deeply negative implications for our access to education and employment, and implement specific and effective reparation policies. (...)
- 8. Investigate all systematic violations against our human rights that have been widely recognized and exposed by different international bodies and to produce reports that specifically address these violations while also following-up on the reports submitted by Intersex movements.
- 9. Provide spaces (such as Human Rights Tribunals) where those suffering such violations and their consequences on our physical and mental health and integrity can make them public. (25)

3.2. Review of human rights recommendations

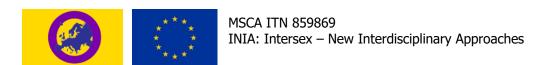
3.2.1. Methodology

For this second review documents that come from international regional institutions or regional human rights monitoring bodies were included. Only documents that can be understood as "soft law", meaning recommendations or declarations were selected. Documents pertaining to the universal human rights system were left out as a similar analysis has been done elsewhere. (13,26) The review includes a summary of the most relevant themes of each recommendation without reproducing the complete content and order.

3.2.2. Summary of human rights recommendations review

3.2.2.1. Europe

In the EU, intersex persons are mentioned in the European Parliament Resolution of 14 February 2019 on the rights of intersex people (27); the European Commission LGBTIQ Equality Strategy 2020-2025 (28); the European Commission EU strategy on the rights of



the child of 2021 (29); and in terms of research there is a focus paper from the European Union Agency for Fundamental Rights on the Fundamental Rights Situation of Intersex People of 2015 (30); intersex issues were also included in the 2019 FRA survey and analysis of results. (31)

On its end, the Council of Europe has also increased visibility of intersex issues through the years. Intersex issues were first mentioned in the Parliamentary Assembly of the Council of Europe Resolution 1952 on "Children's Right to Physical Integrity" in 2013 (32); two years later in 2015 the Commissioner for Human Rights of the Council of Europe issued a report titled: "Human Rights and Intersex People" (33); then the Parliamentary Assembly of the Council of Europe in 2017 issued Resolution 2191 on the "Promoting the human rights of and eliminating discrimination against intersex people." (34) Currently the Committee of Ministers of the CoE is working on a new resolution to address the rights of intersex people. (35)

There are a number of explicit mentions and recognition for the need of redress mechanisms and reparations in the European region recommendations and statements, for instance, the Parliamentary Assembly of the Council of Europe Resolution 2191 (2017) recommends member States to:

7.5.1. **conduct an inquiry** into the harm caused by past invasive and/or irreversible sex-"normalising" treatments practised on individuals without their consent and **consider granting compensation, possibly through a specific fund, to individuals having suffered as a result of such treatment carried out on them.** (34)³

The EU LGBTI Strategy 2020-2025 addresses harmful practices such as non-vital surgery and medical intervention on intersex persons. (28,36) The action points recognizing the rights of victims of crimes and their access to justice programs do not refer explicitly to intersex people, but could give room to maneuver special recognition for intersex people

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³ Bold added.

who have been victims of IGM, or at least in those EU countries where this has been recognized as an unlawful practice.

The strategy recognizes that:

Harmful practices such as non-vital surgery and medical intervention on intersex infants and adolescents without their personal and fully informed consent (intersex genital mutilation), forced medicalisation on of trans people and conversion practices targeting LGBTIQ people may have serious bodily and mental health repercussions. The Commission will foster Member States' exchange of good practice on ending these practices. Forced abortion and forced sterilisation on and other harmful practices against women and girls are forms of gender-based violence and serious violations of women's and children's rights. The Commission will also include an intersectional perspective in the Recommendation on harmful practices against women and girls announced in the Gender equality strategy 2020-2025. (28)⁴

Within the action points to be taken, amongst other things, the LGBTI Strategy aims at

- present an initiative in 2021 to extend the list of 'EU crimes' (Article 83 TFEU) to cover hate crime and hate speech, including when targeted at LGBTIQ people;
- provide funding opportunities for initiatives that aim to combat hate crime, hate speech, violence and harmful practices against LGBTIQ people ('Citizens, Equality, Rights and Values' programme) and **promote the rights of victims of crime, including LGBTIQ people ('Justice' programme**). (28)⁵

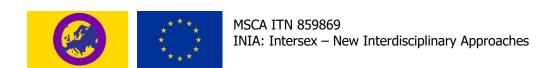
3.2.2.2. Africa

In 2023 the African Commission on Human and Peoples' Rights (ACHPR) issued Resolution Res.552 (LXXIV) 2023 on the Promotion and Protection of the Rights of Intersex Persons in Africa. The resolution recognizes the existence of people with variations of sex characteristics in Africa and recalls different regional legal frameworks relevant for the protection of their rights. Among other things, the resolution recognizes

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⁴ Bold added.

⁵ Bold added.



the harms that non-consensual and unnecessary surgical and other procedures carried out to achieve "genital normalization" on intersex persons have and call State parties of the African Charter of Human and Peoples' rights to:

1. Stop non-consensual genital normalization practices on intersex persons, such as surgical, hormonal and sterilization procedures that alter the sexual characteristics of intersex persons and ensure respect for their rights to make their own decisions regarding their bodily integrity, physical autonomy and self-determination. (37)

The resolution also provides recommendations to State parties concerning the promotion and protection of the rights of intersex persons, to guarantee the best interests of the child concerning medical treatments, the protection of children's rights including protection from abandonment and infanticide; to prohibit discrimination based on "intersex traits and characteristics or intersex status"; to provide counselling and sensitization to families of intersex children; to protect the work of intersex human rights defenders; to allow intersex persons to change their gender registration on legal documents; to guarantee intersex people's access to their medical records; to raise awareness of intersex issues and their rights in society; and to ensure that public officials and public servants are sensitized to the respect and equal treatment of intersex persons, amongst other things. (37)

Regarding access to justice mechanism and reparations, the resolution calls on State parties to:

10. Ensure that human rights violations against intersex people are investigated, perpetrators are prosecuted, and victims have access to effective remedies, including redress and compensation. (37)

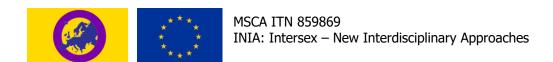


*3.2.2.3. The Americas*⁶

The Inter-American system of human rights is composed of two main monitoring bodies as per the American Convention of Human Rights (ACHR), the Inter-American Court of Human Rights (IACtHR) and the Inter-American Commission on Human Rights (IACHR). (38) While the Court has not dealt with a case related to an intersex person, intersex issues have been considered by the Inter-American Commission on Human Rights.

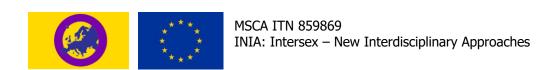
In 2015 the IACHR and its LGBTI Rapporteur included a specific section about intersex 'medical violence' on its first ever thematic report focused on violence against LGBTI persons. (39) In the report the IACHR recognizes the different forms of human rights violations experienced by intersex people because "their bodies do not physically conform to socially accepted standards for 'female' and 'male' bodies". (39) The IACHR also noted intersex activist claims that "have indicated that human rights violations suffered by intersex persons are different from the human rights violations which lesbians, gays, bisexuals and trans persons typically suffer."(39) The Commission raised its concerns about the fact that "sex assignment" and genital surgeries that are carried out without the informed consent of intersex children are standard practice in countries across the American continent. (39) Likewise, the Commission expressed concerns about the fact that these surgeries cause intersex children great harm, are irreversible, have consequences that extend into adulthood including: "chronic pain, life-long trauma, sterilization, genital insensitivity, and diminished or lost capacity for sexual pleasure." (39) In its report the IACHR highlighted that the principle of free, prior and informed consent should guide the decisions concerning a person's body and medical treatments. The Commission recommended the member states of the Organization of American States to "make necessary amendments to policy and law to prohibit medically unnecessary procedures on intersex persons, when it is administered without the free informed consent of the intersex person." (39)

⁶ Also included in the eBrief: Ní Mhuirthile T, Dixit S, Zelayandía González E, Lum S, Mestre Martínez YM, Aegerter A, Suess Schwend A. Human Rights eBrief. INIA: Intersex New Interdisciplinary Approaches, DCU; 2022.



In line with its mandate the Inter-American Commission also issued a series of recommendations to OAS member states. The IACHR urged states to: "(i) conduct trainings of medical personnel and medical community in order to provide adequate treatment and support to intersex persons and their families; (ii) create multidisciplinary groups to provide support and counselling to parents and relatives of intersex children and infants and to provide care and support to intersex persons from childhood into adolescence and adulthood; (iii) conduct awareness-raising and sensitization campaigns at the national level on the short term and long-term effects of 'normalising' interventions on intersex children; and (iv) carry out educational campaigns in conjunction with the ministries of education in order to bring down stereotypes, stigma and invisibility surrounding intersex persons." (39)

Another Inter-American body that has given visibility to intersex issues ever since 2008 is the General Assembly of the Organization of American States (OAS-GA) which is the highest-ranking body of the OAS and is formed by the delegations of all the member states. The OAS-GA has included issues concerning sexual orientation and gender identity in its annual resolution calling for the promotion and protection of human rights. (40) In 2012, following the creation of the LGBTI thematic unit at the IACHR, the OAS-GA for the first time ever included in its annual resolution entitled 'Human rights, sexual orientation, and gender identity' references to intersex people as part of the LGBTI umbrella group. (41) In the resolution the OAS GA called on member states to: "eliminate, where they exist, barriers faced by lesbians, gays, and bisexual, transsexual, and intersex (LGBTI) persons in access to political participation and in other areas of public life, as well as to avoid interferences with their private life." (41) Progressively, in 2013, the OAS-GA finally included a recommendation to all OAS member states pertaining intersex genital surgeries and urged members States to "afford appropriate protection to intersex people and to implement policies and procedures, as appropriate, to ensure medical practices that are consistent with applicable human rights standards."(42) In its 2019 resolution the OAS GA, for the first time ever made references not only to intersex people and the harmful medical practices that affects them, but also embraced 'sex characteristics' as a human rights-based term and as a ground for protection and called out member states to



condemn violence and discrimination based on such ground. (43) To date there are still no specific references to reparations made by the OAS GA.

3.3. Review of academic literature

3.3.1. Introduction

For the academic part of this review, I conducted an explorative systematic review or scoping review. I aim at painting a picture of the landscape of intersex human rights claims and demands present in literature. As Arksey et al. (44) state, scoping reviews are often carried out in order to examine the extent, range and nature of a particular research topic. Scoping reviews are also used to explore research gaps in current literature and determine whether a broader systematic review is called for or if this already exists. Additionally, one of the main reasons one would choose to conduct a scoping review is to summarize and disseminate findings from existing literature and possibly identifying research gaps or policy needs, this falls within the aims of the INIA project.

3.3.2. Methodology

For this scoping review, I followed the different stages of scoping reviews present in the works of Arksey and O'Malley (44) as well as the Joanna Briggs Institute manual for evidence synthesis chapter on scoping reviews. (45)

Stage one in scoping reviews refers to identifying a research question that is better suited to be addressed by a scoping review. In this sense the question guiding this scoping review is to explore the different human rights framings or frameworks intersex activists use to transmit knowledge, explain their needs and gain support for the demands of intersex people as observed in academic literature.

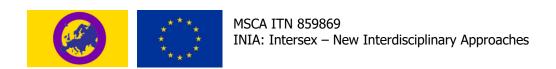


Stage two refers to identifying relevant literature that addresses the research question. In order to explore the different framings intersex activists and movements have used to mobilize their political goals, I looked at scholarship on that topic from the last 23 years. I limited the search to academic works published between the years 2000 and 2022 in order to gain a perspective of the most recent literature. I limited the search to peer-reviewed journal articles and excluded other works such as books, chapters or thesis. Only publications in English were included.

To identify relevant material, I conducted an advanced search looking for social sciences articles with keywords in their title and abstract: 'intersex,' 'DSD,' 'sex characteristics,' 'sex development,' and 'human rights.' The search was conducted in the Web of Science, Scopus, and PubMed databases, because these are three of the most renown and reliable databases with comprehensive and interdisciplinary resources.

The search results showed 272 records, after scanning for duplicates 121 records were eliminated and 151 records were selected to move forward to the inclusion/exclusion stage by reading the title and abstract in order to determine the relevance of the articles.

Stage three refers to study selection. The inclusion criteria during the title/abstract read was set as the following: a record was included for full text review if it explicitly mentioned in the title or abstract 'intersex,' 'intersexuality,' 'DSD,' or any of the other variant keywords and also made references to 'rights,' or 'human rights' or it was very clear that these themes were present in the main text. Records were excluded if they failed to mention 'intersex' or if it was clear that the focus was not even partly about intersex. Records that did not explicitly mention activism or human rights were only included for full text review if activism, advocacy or related political activities were implied in the abstract or if there was a strong indication that the article's subject was closely related to this review's topic. Records that did not include an abstract were included by default in the review.



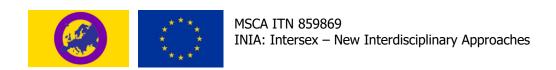
After reading the titles and abstracts of 151 records and following the inclusion criteria, 104 articles were included for full text review. After full text read 50 articles were excluded and 54 records were included in this report. (6–8,19,46–95)

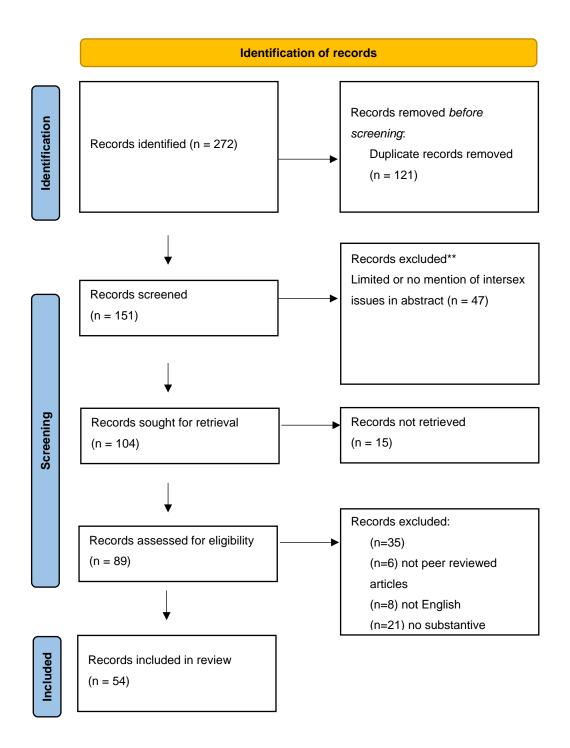
A total of 15 article were excluded because I had no access to them, 6 pieces were excluded because they were not peer reviewed articles and 8 were not written in English; 21 records were excluded because they had no or limited mentions of 'intersex' issues in the main text, the majority used it only as part of the LGBTI acronym without expanding further on any substantive information about the topic through its text.

Stage 4 refers to the charting of data. For this review, I included the following information: Author(s), title, publication year, data base source, main themes observed and main human rights referred.

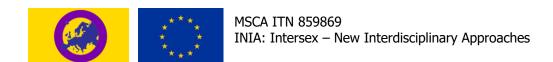
Stage 5: collating, summarizing and reporting the results.

For the analysis of information, a thematic approach (96) was taken, for this part my leading questions were: what themes or issues were present in the documents? If human rights discourses were present, what specific rights are invoked? Which ones had more visibility? Finally, because I wanted to explore literature on reparations I highlight if any references to reparations was present in the literature and if so, how is it framed? What ideas or rights it conveys?





Template from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. Doi: 10.1136/bmj.n71



3.3.3. Results

3.3.3.1. Overarching themes

Following this approach, I analyzed three overarching themes present in the reviewed documents and grouped as "streams":

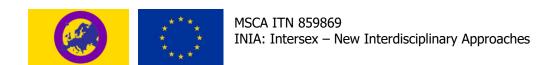
- 1. Human rights international legal frameworks. (6–8,19,46,48,49,51–54,58–61,63,64,68,70,73,78,79,81,82,85,89,94)
- 2. Intersex medical practice and management. (47,51,56,59,62,63,65–68,70,73–75,77,84–86,88–93,95)
- 3. Intersex inclusion in sports. (50,57,69,76,83,87)

These themes often intertwined and cannot be neatly divided. In this exercise I tried to locate the articles in the stream that seemed closer to the centered theme discussed. Subthemes were present in each of these streams.

In the first stream, references to international human rights law (IHRL) were common; they often presented a review of legal or policy frameworks pertaining the rights of intersex persons, for examples those coming from the Council of Europe (CoE), the European Union, or the UN and its special procedures. (6–8,19,46,48,51–53,58,59,61,64,73,78,79,81,89,94)

This stream also included references to intersex activism, particularly its engagement with international human rights institutions and international human rights monitoring bodies (IHMB) and framing of claims as human rights issues. There were also some discussions about domestic legal frameworks, for example the case of Australia, Germany, the United States, Switzerland, and Belgium stand out. (7,19,46,48,53–55,60,61,64,78,79,81,89,94)

Human rights references spoke about bodily integrity, autonomy (6,19,46,48,53,58–60,78,79,81,89) and torture or ill treatment claims, (48,58,60,61,64,68,78,79,81) also

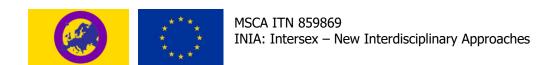


references to discrimination, (19,48,53,54,59,60,64,78,81) claims concerning the right to health, (7,19,48,51,54,61,64,89) and the right to life and private life. (19,48,64,78) Other human rights framings present were that of sexual and reproductive rights and harmful practices. (48,53,58,60,61,64,78,81)

Children rights claims were present in many ways, for example concerning children's agency, the principle of the best interest of the child, their right to identity, development, and their right to be heard. (48,51,59,61,63,64,70,78,81,89) There were also mentions of parents' rights, often noticing possible conflicts between the rights/views of parents and those of children. (51,59,61,63,70)

Concerning the second stream, articles centered in medical practice also included to some degree discussions on human rights, often without going into details concerning legal implications or state or individual responsibility for human rights violations. Other subthemes include the history of medical practice, current medical protocols, matters that are seen as improvements or progress regarding medical treatments, specific variations, diagnosis and specific lines of treatments. (47,56,65,67,68,73–75,88–93,95) Critical perspectives of current and past medical protocols were also present and so were activists' and human rights concerns, but were not always centered to the discussion. (59,62,66,68,73,75,84,88–90,92,93,95) Articles in this stream also included both intersex and DSD terminology as well as some mentions of variations of sex characteristics.

As a matter of explicit rights mentions, many referred to personal or bodily integrity and autonomy as the main human rights concerns. (59,62,65,68,70,84,89) Other articles mentioned children's autonomy, right to an identity, right to development, right to be heard, and right to be protected from abuse and violence. (51,59,68,75,86,89) Interesting discussions about children's rights *vis a vis* parental rights were also observed. (59,70,75,84,86,93) There was limited mention of any rights or human rights in some articles in this stream. (62,66,67,84,88,91,93,95)



Concerning the third stream about sports the main human rights concern expressed was discrimination. (50,57,76,83,87) Other themes relate to fair play and sports rules regarding sex/gender, and sex-testing in sports, and the medicalization and pathologization of intersex variations. (50,57,69,76,83,87) Another issue present as well was the specific case of Caster Semenya. (50,57,76,87) The comparison of terminologies preferred show that the DSD frame is more common in sports related literature than 'intersex'.

Overall, in all streams there was a limited mention or references to social, economic and cultural rights, other than the right to health. Mentions to a disability rights approach also continue to be marginal.

3.3.3.2. Reparations and access to justice

The issue of reparations, redress or access to justice mechanisms was not particularly a main topic addressed in human rights literature, only 5 records were coded as mentioning any idea or referring to any form of reparations or justice claims or redress. (19,48,53,64,78) In two pieces of this review pertaining to Morgan Carpenter, the author makes references to this topic. In a 2020 piece Carpenter recalls how access to justice and remedies have been limited to intersex persons; this, in view of the author, is greatly due to stigma, the effect of limited disclosure of clinical records and unnecessary statutes of limitation which hamper the capacity of individuals to seek redress. (53) In another piece the author expands on what the inclusion of the right to truth in the Yogyakarta Principles plus 10 would mean for people with diverse sex characteristics. (19)

Bauer et al. also address the topic of reparations, in their 2020 article, the authors highlight international human rights frameworks, for example that of the Committee against torture, referring to "the right to access to redress and justice for victims of torture, including to fair and adequate compensation and the means for as full rehabilitation." (48) The authors also show concern over the barriers intersex persons have to access ordinary justice mechanisms, they note that "Statutes of Limitations"



render redress and access to justice for childhood IGM difficult or impossible in many nations". (48)

In a 2019 piece, talking about access to redress and reparations, Garland and Slokenberga state that "several national medical-ethics organizations have warned that protection for intersex children requires enhanced remedies, including criminal penalties and additional time to seek redress, where clinicians physically harm children through violations of their right to refuse any gender-conforming procedures." (64)

In an analysis of the ECHR jurisprudence and standards, Mestre argues that current medical practice that does not consider the agency of the person might be in violation of the prohibition against ill treatment and torture, likewise, she argues that the ECHR has emphasized that "states have a positive obligation to prevent the commission of ill-treatment and investigate the possible violation of human rights that covers itself with the redress of the damage, according to Article 13 of the Convention." (78)

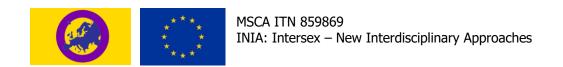
4. DISCUSSION

4.1. Human rights framings

The three reviews carried out here show that human rights discourses are commonly evoked by intersex activists and social movements to portray their claims. The main demand highlighted by intersex activists is to put a stop to medically unnecessary surgery or treatments that are not consented by the affected person, however this claim is not alone. As mentioned in the gray literature⁷ review there are many other demands directly connected to this issue and other human rights violations experienced by intersex persons, for example stigma, discrimination, lack of access to health care, including lack of psychosocial and peer support.

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⁷ Consistent of activist declarations and international recommendations.



4.2. Access to justice and reparations

Intersex people suffer multiple forms of direct and indirect discrimination, and this also applies to accessing redress mechanism and reparations. As Bauer et al. (48) highlight, because surgeries and other invasive unnecessary medically approved treatments have been normalized they often go unquestioned. In some jurisdictions such as Canada, intersex genital normalizing surgeries are barred from criminal liability. (97) In 2021 Human Rights Watch started documenting efforts in the United States to shield from criminal responsibility these forms of medical abuse. (98)

Another issue is the aspect of statute of limitations, usually people have a period of time to present a claim before the criminal justice system, statutes of limitation are intended to be a procedural guarantee so people do not have to 'fear' criminal responsibility for the rest of their lives, a common classroom example would be someone who committed theft in their teens do not have to worry about been prosecuted into their old age.

In the case of intersex persons, however, as highlighted by the OHCHR, "intersex organizations have suggested that statutes of limitations unnecessarily limit access to redress for intersex individuals who have suffered unnecessary or inappropriate medical interventions without their consent during childhood or adolescence." (1) Bauer et al. point out that "statutes of limitation render redress and access to justice for childhood IGM difficult or impossible in many nations." (48) This is because violations committed against them, for example surgery or unwanted medical treatments, are carried out during childhood and it takes time for people to grow up and be legally able to bring a claim of their own to the courts. On the second hand because these human rights abuses have been normalized in medical practice and common culture, it takes extra time for the person to decide if they want to bring a claim to action or not. An additional barrier exists in those cases where people are unaware of surgery or treatments forced upon them because of medical secrecy, or in cases where they know, but the medical records do not exist or are not available. Precedents exists however when in cases of child abuse,



statutes of limitation are extended or suspended until the person is old enough to carry out a claim. (1)

4.2.1. The right to truth and a proper investigation

Regarding specific forms of reparations, what stands out in the review is the right of intersex people to know the truth about what happened to them. The OHCHR has highlight that "[e]xperts recommended capacity building for judicial systems to ensure that intersex people have effective access to justice. Victims of human rights violations are entitled to truth, justice, reparation, rehabilitation and other remedies. In some cases, access to treatment may be reparative." (1) This was also considered in the YP+10. (16)

Regarding the right to truth, the standard of the Inter-American system of human rights is quite helpful. The IACHR has considered that the right to truth is closely linked to the person (or family members) to know what happened. The right to truth is not necessarily an individual right, meaning it is not necessarily exhausted by the production of a private report, but also can be a collective form of reparations. (99)

4.2.2. Recognition of harm

Many of the activist claims in the gray literature review spoke of the need for a recognition of harm. Both the Darlington Statement and the Yogyakarta Principles plus 10 also highlight the need for a public apology. The Yogyakarta Principles plus 10 for example speak about social dissemination of findings about past human rights violations, through commemorative dates, acts of public recognition and apology, museum and cultural exhibits and inclusion in educational curricula. (16)



4.2.3. Individual redress and compensation

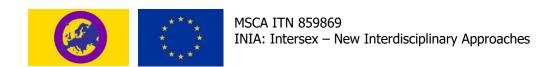
Other forms of reparations observed in this review were specific rehabilitation measures for people who have suffered from abusive medical treatments and surgeries. As noted by the Vienna Statement intersex persons who have gone through these treatments can have health needs because of the surgeries and treatments, States and health policies should consider this. (21) Activist statements also highlight the need of psychosocial care and peer support, especially for victims of human rights abuses. (22,24) Redress as a form of financial compensation was also highlighted, for example the Parliamentary Assembly of the Council of Europe Resolution 2191 speaks about the creation of a specific fund.

5. CONCLUSIONS

A review of the above documents confirms that the demand for bodily integrity and to end medically unnecessary and non-consented surgeries and medical treatments is present in activists' and human rights documents in different regions.

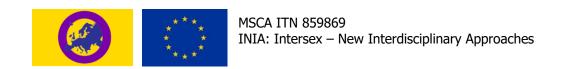
The review also suggests that access to redress procedures and mechanisms, and the right to effective remedies and reparations are demands that are already present in different activist groups' documents. In this review the most extensive interpretation was found in the Yogyakarta Principles plus 10, this might be in due to the fact that they consider already existing interpretations of IHRL, which in itself already has extensive literature and jurisprudence on the topic of redress and reparations. (100,101)

Except for the Yogyakarta Principles and YP+10, most activist documents reviewed here do not go into details of what reparations and redress would look like, but there are two elements that stand out when it comes to access to justice and reparations, one is the acknowledgement of harm and the other one is redress. The Darlington Statement, for example, includes a demand for a public apology as a form of recognition. Other measures suggested by the Yogyakarta Principles plus 10 is publicity of past rights violations for



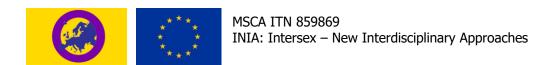
example by commemorating dates, museums, events, or inclusion in human rights education curricula.

More research is necessary on the topic of redress and reparations from a human rights perspective. While this topic is addressed in most of the activists' declarations and statements examined in this report, only a limited number of international recommendations have called for redress and reparations. In terms of intersex studies and human rights scholarship, this topic is mostly left unaddressed, only marginal mentions were found in this review. In this sense it is not only recommended that researchers put more attention to the issues of redress and reparations but also that policy makers and human rights monitoring bodies start to include them in their recommendations.

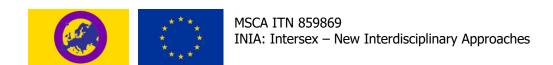


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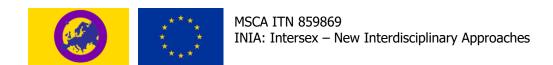
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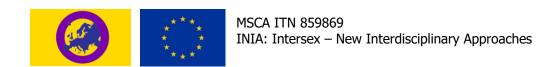
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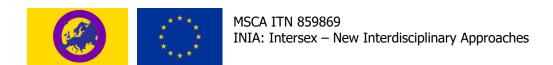
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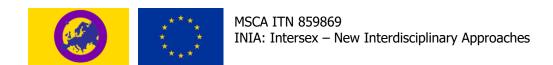
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