Translation of intersex rights: from medical collaboration to human rights opposition : The intersex movement from the “Consensus statement” (2006) to 2015

Aegerter, Audrey Alessandra Pascale

How to cite

AEGERTER, Audrey Alessandra Pascale. Translation of intersex rights: from medical collaboration to human rights opposition : The intersex movement from the “Consensus statement” (2006) to 2015. Master, 2020.

This publication URL: https://archive-ouverte.unige.ch/unige:156906

UNIVERSITÉ
DE GENÈVE
CENTRE INTERFACULTAIRE
EN DROITS DE L'ENFANT

Sous la direction de Prof. Karl Hanson

Translation of intersex rights: from medical collaboration to human rights opposition

The intersex movement from the "Consensus statement" (2006) to 2015.

Présenté au
Centre interfacultaire en droits de l'enfant (CIDE) de l'Université de Genève
en vue de l'obtention de la
Maîtrise universitaire interdisciplinaire en droits de l'enfant

par

Audrey Alessandra Pascale AEGERTER

de

Oberwil im Simmental, Berne

Mémoire No : CIDE 2020/MIDE 19-21/01

Jury :
Prof. Karl Hanson
Mme Ludivine Richner

SION
Août, 2020

Acknowledgement

I am forever grateful to the European and French-speaking intersex communities as well as the Réseau Francophone de Recherche sur l'Intersexuation, which have supported me on a personal, political and intellectual level, throughout my journey. Some of the people I want to name specifically are Deborah Abate, Janik Bastien-Charlebois, Mathilde Abel, Kitty Anderson, Luca Boehm, and Irene Kuzemko.

I would also like to express my deepest appreciation to some of the staff members of the Institute for Children's Rights Studies at the University of Geneva; Elena Patrizi, Professor Karl Hanson and Mary-France Mathis. All three have been of great support. Despite social distancing and lockdown, Professor Karl Hanson's supervision and guidance, throughout this research project, have been extremely valuable.

I am deeply in debt to my parents, Elisabeth and Pascal Aegerter, who have always supported me, and without whom, I would not have had the opportunity to follow my political and intellectual ambitions. As well as my sister, Florence Aegerter, who has proof read parts of this paper. Other parts have been proof-read by Adeline Berry, Axel Keating, Daria Abrosimova, Louise Luthy, and Steph Lum, to whom I am extremely grateful.

Lastly, the completion of this paper would never have been possible without the interviewees who agreed to be cited in this paper without being anonymised; Curtis Hinkle from OII, Dan Christian Ghattas from OII Europe, Daniela Truffer and Markus Bauer from Zwischengeschlecht.org/StopIGM.org, Georgiann Davis from the University of Nevada, Ins A. Kromminga from OII Germany, Kris Grünter from OII Belgium, Mauro Cabral from GATES, Morgan Carpenter from IHRA, Alice Dreger from ISNA and Silvan Agius who was, at the time, working for ILGA-Europe and the Maltese government.

Table of abbreviations

AA	-	Alcoholic Anonymous
ACT	-	Australian Capital Territory
AGGPG	-	Arbeitsgemeinschaft gegen Gewalt in Pädiatrie und Gynäkologie
APA	-	American Psychological Association
CAT	-	Convention Against Torture
CEDAW	-	Convention on the Elimination of Discrimination against Women
Consensus statement	-	Consensus Statement on the Management of Intersex Disorders
CRC	-	Convention on the Rights of the Child
CRPD	-	Convention for the Rights of Persons with Disabilities
DSD	-	Disorder of sex development
DSM	-	Diagnostic and Statistical Manual
EBM	-	Evidence-Based Medicine
HSM	-	Health Social Movement
ICD	-	International Classification of Diseases
IGLYO	-	International Lesbian, Gay, Bisexual, Transgender, Queer & Intersex Youth and Student Organisation
IHRA	-	Intersex Human Rights Australia
IHRM	-	Intersex Human Rights Movement
IIF	-	International Intersex Forum
ILGA	-	International Lesbian, Gay, Bisexual, Transgender and Intersex Association (previously: International Lesbian and Gay Association)

ISNA - Intersex Society of North America

LGBT - Lesbian, Gay, Bisexual and Transgender

LGBTI - Lesbian, Gay, Bisexual and Transgender

LWPES - Lawson Wilkins Pediatric Endocrine Society

OHCHR - Office of the High Commissioner of Human Rights

OII - Organisation Internationale des Intersexués

TGEU - Transgender Europe

UN - United Nations

USA - United States of America

VSC - Variation of sex development

WHO - World Health Organisation

Abstract

Around the time of the *Consensus statement on the management of intersex disorders* in 2006, controversies within the intersex movement materialised. These controversies mainly articulated themselves around the adoption of a new medical language, namely Disorders of Sex Development, and the endorsement of this wording by the Intersex Society of North America. A decade after that statement, and the refreshed medical guidelines, the question of intersex bodily integrity has been increasingly institutionalised within international and regional human rights mechanism. This research aims to understand the role of the *Consensus statement on the management of intersex disorders* in this process and more specifically, the controversies within the movement that surrounded this event. By conducting problem-centred interviews with leading voices of the movement at the time, different phenomenon could be identified. A feeling of anger resulting from the pathologisation of intersex bodies in the new standards of care, motivated the creation of an international network of intersex organisations. Strengthened from the international community and new online communication tools, a different approach to activism emerged, crystallising its claims during international intersex forums in 2011, 2012 and 2013. However, despite international recognition, it seems that the movement still faces difficulties to bring its demands forward as a result of the newly endorsed nomenclature.

Table of content

List of figures

Introduction

When hermaphrodites started having attitude in the 1990s, a collective narrative was forming to challenge the sex dichotomy. With the creation of online and offline groups, a community blossomed, and created new terms to address "this". With an article titled *Not having the right to say what we were not told we were*[1] (Guillod, 2008), Vincent Guillod addresses the recommendation of the first standards of care, developed in the 1950s, calling on early operations and secrecy. But what is "this" referring to? "This" concerns a variety of different words such as hermaphrodites, intersexuals, or intersex as well as people with a disorder of sex development (DSD), or a variation of sex characteristics (VSC). All point towards the same group but have different connotations. Thus, the UN defines intersex people as individuals who are born "with sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies" (Fact Sheet intersex, n.d.). Yet, the *Consensus statement on the management of intersex disorders* (Consensus statement) defines DSD as "congenital conditions in which development of chromosomal, gonadal, or anatomical sex is atypical" (Hugues, Hook, Ahmed, Lee, LWPES Consensus Group & ESPE Consensus Group, 2006, p. 554). In a context of tension between human rights and medical standards, choosing a terminology is not neutral. Considering the objective to understand some of the conditions for the emergence of a global intersex human rights movement (IHRM), this paper uses the predominant language in this context. Therefore, intersex is preferred as a political term to address people who identify with the term, and the movement. Variation of sex characteristics (VSC) however, is used when addressing legislations, medical aspects and people who do not identify with the term intersex. Consequently, all intersex people have a VSC, but not all people with a VSC would call themselves intersex. Nevertheless, when historically or contextually relevant, other terminologies will be used.

Since the 1990s' an intersex movement started to emerge in the United States of America (USA) and Europe. New technological tools, such as the internet, offered the opportunity for dialogue without limits of space nor shame (Chase, 2002a; Guillod, 2008). Even if some patient groups already existed to address the particularities of specific variations, organisations such as the Intersex Society of North America (ISNA) in the USA and the Arbeitsgemeinschaft Gegen Gewalt in Pädiatrie und Gynäkologie

---

[1] Original "Ne pas avoir le droit de dire ce qu'on ne nous a pas dit que nous étions"

(AGGPG) in Germany included people with any VSC. Their objective was to stop unconsented surgical and hormonal procedures on children and infants. Most of the members were amongst the first generation of people subjected to these treatments that are, in an international human rights law context, considered harmful practices, genital mutilations, and tortures (Crochetti, Arfini, Monro, Yeadon Lee, 2020). Contemporary, intersex studies in social science are generally part of gender studies or feminism. However, the movement can be analysed through, what Morgan Holmes (2008) calls, straight bioethics. According to Holmes' statement that a child with a VSC will not be recognised as a person unless they undergo medical treatments; and that disabled individuals struggle to access person status (Cameron, 2014), this research will use frameworks specific to the LGBT and disabled movements. Intersex activism is perceived at the crossroad between the LGBT, feminist, disabled and children's rights movements, taking an intersectional approach as defined by Crenshaw (1991); a concept of systematic and structural oppressions that comes from more than one oppressed trait.

With a clear objective to be interdisciplinary and articulate the research in the fields of sociology, history, and politics, this paper aims to respond to the question: how did the Consensus statement participate in the emergence of a global IHRM? Therefore, it will use theories and concepts coming from social studies. These encompass Foucault's work on politics and power and their application in the health sector through medicalisation, a concept that will be defined using the work of Fassin, Conrad and Zola. The research of Neveu, Kreisi or Tili will lead the discussion on social movement, but Epstein's and Williamson's theories on health social movements (HSM) will highlight the particularities of activism in medical institutions. This paper understands the international and regional human rights law system as political tools for social movements to reach a change in a social order. Therefore, the theoretical part gives an explanation of the process to reach social justice, called translation.

Being an intersex person and advocate myself, I see a need for additional knowledge on intersex/VSC coming from the intersex community itself and with a human rights perspective. Intersex people are not only research or medical subjects but also actors of their rights and situations. Having women and queer people lead gender studies has, for example, made a significant impact on the understanding of the situations of oppressions they face in a patriarchal system. Being aware of my bias in this research, I took specific care not to let my personal motivations lead my findings and results. To be transparent, the chapter 3.4, is committed to the specificities of my role as an intersex researcher in intersex studies.

Chapter 1. Theoretical part

1.1. Powers and politics: a battlefield

One of the prominent scholars studying the notion of power and how it shapes politics, was Michel Foucault. While there is not a definition-fits-all of power, this paper will take on a Foucauldian approach to the concept. Foucault spoke about sovereign-power, disciplinary-power and bio-power (Lilja, Vinthagen, 2014). The following chapter aims to define these terms, as they are critical tools in the investigation of the emergence of intersex activism. Furthermore, it will address the notions of politics; which definition consists of a societal dialogue opposing different points of views to influence a change in a social order. An objective that all social movements share.

When Foucault (1984/1997) mentions power, he transgresses the essentialist vision of power being exclusive to a specific group; creating a dichotomy between powerful and powerless people. In Foucault's understanding, power finds itself within a relationship, where someone (or a group) tries to control the conduct of someone else (or another group). Power is in every relationship and enables every individual (or group) to resist to a situation with more or less efficiency. Having the option to show resistance, in that sense, is a sign of freedom. Nevertheless, domination exists even within the state of liberty; hence power relationships can be asymmetrical. Accordingly, some might have more capabilities, and leveraging a situation might be more straightforward for them. However, even if a dominant class has more power in a specific power relationship, the dominated one can pressure for change. This notion of power is an essential aspect of this paper, as patients or people who oppose the medical complex face a powerful institution, making their demands more challenging to put in place. In *Truth and power*, Foucault (1976/1980) claims that power runs through the social body and uses the image of a war to illustrate politics. Foucault identifies three types of power relationships; sovereign-power, disciplinary-power and bio-power. The first is repressive and makes use of the law or other types of regulations to prohibit and censor. Disciplinary-power, however, gives directions to humans, who then take on similar conduct or language. Knowledge-power is part of disciplinary-power as knowledge, according to Foucault, is a type of power. It has the authority of the 'truth' and has the ability to "make itself true" (Lilja, Vinthagen, 2014). Disciplinary-power is both, productive and repressive, as it enables a change. Lastly, bio-power takes care of life by constituting humans as subjects. Bio-power is exercised by the state or specific private benefactors (Lilja, Vinthagen, 2014).

In the political scene, there are two main forces, according to Foucault (1974/1997); technologies of power and technologies of the self. The first is participating in the determination of behaviours for domination purposes or objectifying individuals. However, the rise of new technologies of power are making the connection between body and history more complex. The second one is enabling individuals "to effect by their own means, or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being" (p.225). The encounter between technologies of power and technologies of the self, gives a direction to human behaviours. With the development of new disciplines and techniques, the classical period fostered a new way of thinking and controlling the body. With the rise of capitalism and the creation of new means of control, the insertion of bodies into the production machinery was made possible (Foucault, 1976/1978). Consequently, a separation was occurring between bodies; the ones that could be utilisable for profits and those that were not. Different institutions were built to guarantee the pace of production systems and separating the people perceived as profitable from those who were not, such as prisons, asylums and hospitals (Hayes & Hannold, 2007). Capitalism enabled humans to grasp what humanity entails; more than merely being the sum of biological traits; it is the interconnection between history and biology (Foucault, 1976/1978). Humanity consists of the physicality of the body, the socio-economic conditions of existence, the individual and collective welfare as well as modifying forces (Lazzarato, 2002). Consequently, anyone engaging in society is changing more or less directly the power relationship, and the lived realities of society. The next two chapters will highlight the debate between technologies of power and technologies of the self that will be especially important when analysing the intersex movement and HSM. First, it will look at the process of medicalisation as a type of technology of power as it determines specific human traits for domination purposes and objectifies the people as being sick. The second will articulate itself on the study of HSM, international human rights law system and finally take on the political theory of Miranda Fricker (2007) on epistemic injustice. While these are certainly not the only examples of technologies of power and self, they will outline the theoretical frameworks necessary to analyse the phenomenon and shared experiences of political actors in the field of intersex and VSC.

1.2. Technologies of power: medicalisation and pathologisation

Through the discoveries and knowledge medicine has acquired in the last century, it has become one of the most powerful institution. While it is inevitable that medicine is necessary to heal those who are sick, and to increase the quality of lives, sometimes there are abuses in medical authority. This chapter will discuss the notions of medicalisation, pathologisation and biological citizenship as technologies of power. These notions are important when analysing the intersex movement, as they are amongst the main areas of controversy. What is considered as a pathology and ought to be treated and what is a natural variation of human diversity? Is the pathologisation of intersex variations a way for medicine to reassert its authority over intersex bodies, and objectify them, as would disciplinary-power suggest? While this will not be answered here, the theories outlined in the following chapter, are used in the analysis part of this paper, to understand the interconnection between the intersex movement's demands, lived realities and the medical guidelines.

As mentioned before, medicine is one of the most powerful institution. While there is not a unique answer, as to what makes medicine this important, Karkazis (2008) claims that the power of medicine and science lies "in their ability to define what is natural, to name nature and human nature, and in their claim or hope to return individuals to a more natural state or way of being" (p.11). This statement points toward the concept of the social construction of nature and specifically, deviance. A social construction as a deviance is not inherently wrong, nor unnatural, but if framed that way, medicine has the power to intervene and treat. Uncontestably, certain conditions or deviances however are medical problems that need care to return to a state of health. On the contrary, other become medical through a process of medicalisation, defined by Peter Conrad (2006) as "a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders" (p. 4). In that sense, medicalisation is a way of exercising power because a nonmedical problem suddenly becomes part of medical authority. Conrad (2006) argues that the process of medicalisation is bidirectional, meaning that there is, on one side, medicalisation but also, on the other side, demedicalisation. The latter occurred when a problem that was medicalised is not defined using medical terminologies and cannot be treated anymore. Both medicalisation and demedicalisation can happen from the outside-in or the inside-out. In other words, from the medical institution or groups of people with a deviance. Alcoholism, for example, has been medicalised as a result of the Alcoholic Anonymous (AA) movement. The medicalisation of alcoholism was a demand of the movement to access proper care. Other social movements, such as the disability movement or the lesbian, gay and bisexual movement, have engaged with more or less success to reduce the medical jurisdiction over their status. Interestingly, Foucault (1984/1997) explains that medicalisation is both a mean of oppression and a mean of resistance. The lesbian, gay and bisexual movement asking: "If we are sick, then why do you [the medical institutions] condemn us, why do you despise us?" (Foucault, 1984/1997, p. 168) illustrates this situation perfectly. With the transition from a medical model to a social model of disability, underlined in the Convention on the Rights of Disabled People (CRPD), the disability movement calls for demedicalisation of their status. Despite not fitting medical standards of naturality, disabled people must receive person status, instead of sick or patient status (Cameron, 2014).

Many sociologists and anthropologists are using medicalisation to address issues of over-medicalisation or inappropriate medicalisation, writes Sholl (2017), who tends to be critical with regards to that trend. He regrets that the fine line between medicalisation and pathologisation is often blurred and makes medicalisation seem inherently wrong. He writes that pathologisation involves ways in which conditions are labelled as pathologies or pathological in definitions or diagnosis. On the contrary, medicalisation involves "various types of medical responses and interventions or treatments that are justified in relation to medical practice" (Scholl, 2017, p. 266-267). While pathologisation and medicalisation often overlaps, Scholl (2017) argues, this is not always the case. Fassin (2011) suggests that certain conditions are not considered as pathological but still are medicalised. This is, for example, the case, when looking at the AA example Conrad (2007) gave. The AA movement wants medicalisation to access to medical care but alcoholism is not considered a pathology per se. On the contrary, disabilities are medicalised and pathologised, so were also LGBT people (and still are in certain countries).

In an essay, Zola (1972) argues that since the 20th century, medicine has taken an increasing importance in society and becomes an institution of social control. In the name of health, an increasing number of human existences are medicalised, and medicine holds the power to control them. This process is done insidiously and influences not only medicine but also other institutions such as law or religion. According to Fassin (2000), the status a person gets attributed, whethere it is sick status or person status, is a combination of nature and culture. A person "receives" sick status because of cultural standards and values that perceives a behaviour or a trait as bad, as deviant and therefore as something that ought to be treated.

In their book *Deviance and medicalization,* Conrad and Schneider (1992) propose a five-step model to the medicalisation of deviances. While the fifth step of this model is the most relevant for this research, all five will briefly be explained in the following part:

1. **Definition of a behaviour as deviant**: the deviance is already socially perceived as wrong, but first medical definitions emerge.
2. **Prospecting medical discovery**: the deviance is announced in medical journals, conferences or books. The discovery is descriptive and includes diagnosis, aetiology and treatment.
3. **Claims-making; medical and nonmedical interests**: different stakeholders are interested in the deviance and are engaging in claim-making activities. Nonmedical stakeholders also take part in claim-making activities, by making the issue visible to a broader public through publicity, campaigning, and supporting law and policymakers. Due to the higher visibility, nonmedical claim-makers invite the public to engage with the new designation. Furthermore, they challenge medical claim-making on the basis of previous medical knowledge and pointing towards discrepancies.
4. **Legitimacy: securing medical turf**: In addition to rhetorical claims, the deviance is pushed through instrumental designation. For instance, a state arbitration can recognise the medical viewpoint as valid or not. This can happen by going to court and using juridical systems. A particular social control may be granted by the state to medicine which "may become the agent of social control for the state" (p. 270).
5. **Institutionalisation of a medical deviance designation**: The deviance receives a certain sense of permanence and legitimacy with its institutionalisation. The deviant categorisation gains in symbolic and instrumental acceptance. Institutionalisation can happen with medical or legal classification systems, official diagnosis insertion in official manuals or transcripts such as the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) or the International Classification of Diseases (ICD) as well as with bureaucratisation and the creation of large organisations.

Georgiann Davis (2015) completes this model with the addition of a sixth step consisting of infights between people whose deviance is newly institutionalised. She suggests that there is opposition towards the medical establishments, and among persons whose deviance is being medicalised. Davis (2015) further claims that the name affects, at a personal level, the acquisition of a biological citizenship. Building upon Rose and Nova's conceptualisation of biological citizenship in 2004, she argues that on an individual level, this citizenship addresses how the description of personal traits is done using biomedical language. In other words, do people use the medicalised language to describe themselves, and how does this give them access to biological citizenship?

Hayes and Hannold (2007) propose a three-step approach to the medicalisation of disabilities. For the authors, medicalisation goes through the maintenance of a medical knowledge/power differential, the reinforcement of the 'sick role' and the objectification people with disabilities. The theory dissects the legitimacy and institutionalisation of a deviance. Taking a Foucauldian approach, the authors write that "the power of institutional standards originates when people interpret their world in accordance with these standards and elect to abide by them" (p.357). This statement seems to be in adequation with the notion of social construction previously mentioned. Furthermore, they cite Freidson, who in 1970 explained that notions such as normality or desirability are inherent to the notions of illness and mortality. Consequently, the diagnostic power of physicians is central to define illness. Diagnostic power shows that health and sickness are both social constructions that evolve, depending on social and historical evolutions or scientific discoveries. The social and historical evolution of sickness will be further discussed in the analysis of this paper and especially the role the Consensus statement played in the case of VSC. In accordance to the previous statements, Fassin (2000) writes that society asserts a sanitary status to certain realities based on its set of values. The process of medicalisation and demedicalisation participates in these changes but also evolve within a social, historical and scientific environment. Sick-role is a social status that is tied to characteristics such as passivity and powerlessness. Patients are the recipients of a treatment, and healthcare professionals the active providers of that treatment. By giving someone a diagnosis, the subjective reports of the patient become an objective observation of the clinician (Hayes & Hannold, 2007).

Medicine developed objectivity with, amongst other, evidence-based medicine (EBM). In an article in Seminars of perinatology, David L. Sacket defines EBM as "Integrating individual clinical expertise with a critical appraisal of the best available external clinical evidence from systematic research. Individual clinical expertise means the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice" (Sacket, 1997, p. 3). Sacket (1997) also refutes the claim that EBM turns medicine into a cookbook giving a one-way-street to healthcare. Much more, EBM is combined with a bottom-up approach including both individual patient care and clinician's expertise. While EBM is advantageous to some regard, Karkazis (2008) maintains that it strengthens the medical authority. Evidence-based standards are not, as one might believe, objective, transparent or universal, but emerge from a knowledge that is always socially shaped and never neutral. That is also how Foucault (1976/1978) defines knowledge-power. In addition, to be able to engage in evidence-based claim-making, a particular set of factors need to be taken into consideration, such as the involvement of the patient in the research. This involvement underlines the necessity of disclosure and accessibility of concerns regarding their condition, treatment, and the science around it. This does not refute that EBM increases the objectivity of the findings, but it is not and never will be "totally" objective. Fassin (2000) argues that the objectivation process contributes to the production of health, but it never should be separated from subjectification. The latter opens up to a political space within medical establishments. For him, politics is a three-step process; first, it consists of incorporating inequality of bodies in social orders; second a power to heal and treat a disease by people that are perceived as competent to do so and finally the government of life; thus bio-power. Therefore, the definition of health and illness are part of the technological power and are inherently political.

1.3. Technologies of the self: subjectivity as opposition

Foucault (1974/1997) defines technologies of the self as "the action to effect *by their own means*, or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being" (p.225). What is particularly interesting in this definition is "by their own means", opening up to the concepts of agency. In the following three chapters, theories around social movement are firstly outlined, then, secondly, a discussion follows on the usage of the international human rights law system to achieve social justice and finally the political-philosophical theory of epistemic injustice is explained. These three chapters are essential when analysing the emergence of a global IHRM and its utilisation of international and regional human rights mechanism.

1.3.1. Social movement and radical health social movements

"A social movement that only moves people is merely a revolt. A movement that changes both people and institutions is a revolution" (King, 2010, p.155) wrote Martin Luther King in the *book Why we can't* wait published in 2010. The statement illustrates the different definitions, goals and successes of social movements. While, it is etymologically clear that social movements entail an objective of change, of drifting away or drifting towards, the ways to achieve movement are different. Multiple forms of social movements exist and distinguish themselves from one another in multiple ways. The following part of this chapter, aims to define social movements and gives more precisions concerning HSM or patient movements.

Defining social movements is a challenging task. When some, such as Sidney Tarrow (1976) defined social movements as “a sustained challenge to powerholder in the name of disadvantaged populations living under the jurisdiction or influence of those power holders” (p. 874) other scholars, tend to have a less essentialist approach of the definition. Erik Neveu (2005) maintains that social movement should not be defined as dominated, excluded or marginalised groups of people. Rather, he claims, this domination, exclusion or marginalisation is found within a relationship with another entity on a specific matter at a specific time. This is in line with Foucault’s notion of power finding itself in a relationship (Foucault, 1984/1997). In other words, one can be marginalised to specific regards, yet part of the dominant group to other regards. According to Tilly (1996), social movements arise from complex social interactions, and Neveu (2005) argues that there is a collective dimension to social movements. Several social actors unite and converge around common political demands. These reflect an intentional desire to move collectively in the defence of an interest. Social movements form a “collective enterprise aiming to establish a new social order (Blumer, 1946)” (Neveu, 2005, p.9). Neveu (2005) further explains that the social order a movement is aiming towards does not have to be “new”, but can also be a resistance to an occurring change. For example, LGBT advocates demand, amongst other things, marriage equality. Other movements oppose to this change and unite against it. La Manif’ pour Tous, in France, is an example of a movement that is built in resistance to an upcoming social change and forms a counter-movement. Their political demand is that wedlock stays between cisgender men and women, and that a family includes a father and a mother. Therefore, it is a counter-movement to the LGBT movement. For Neuveu (2005), not everything that is around life in society is political, but the politics of an action is when one calls upon political authorities to answer public intervention. A political authority could be the government, administration services or, as mentioned previously; the medical establishments.

Figure 1. A matrix of social movement trajectories (Neveu, 2005)

Social movements do not only change (or try to change) a social order but can also modify their strategy. One can observe the trajectory and evolution social movements, with the help of the matrix developed by Kreisi in 1993 (Figure 1) but taken, in figure 1, from Neveu (2005). The matrix separates movements with regards to the level of participation required by movement's members and the direction of the organisation. The degree of participation in a movement can vary drastically; going anywhere from financial contribution through membership fees to public and political engagement. With inward or outward organisation, the matrix is responding to the question to whom the services are targeted. With an inward organisation, the services are directed to the organisation's members only. For example, peer support groups or emergency hotlines that members can take into consideration. On the contrary, in the case of outwards organisation, the services and activities are directed towards external parties, such as political institutions. Four types of movements arise from the matrix: services, political representation, self-help and political mobilisation. While this research mainly addresses political mobilisation against medical establishments, it is essential in the context of this paper to also give a brief definition of self-help and understand its importance. Epstein (2007) claims that self-help and political mobilisation often overlap. Imagining a movement, as either a self-help group or a political mobilisation, is too simplistic and does not take into account hybrid forms of organisations. Neveu (2005) describes self-help groups as organisations depending on the participation and support of its members for the services to have an essence. Furthermore, he writes that self-help movements can contribute to make activism survive and thrive. For example, in the case of patient initiatives, Steven Epstein (2007) argues that an illness identity forms a collective narrative, which gives a direction to the movement's demands. For instance, during group discussions finding place in self-help groups, data can be gathered to politicise some of the questions and an experiential expertise is forming. Brockmann (1976) dissociates experiential from professional knowledge. Specialists in their field develop the latter, while the first one is the knowledge that a patient knows about themselves, about their personal history and case. Simpson (1996) argues that through self-help groups, experiential knowledge goes beyond personal history, and incorporates the stories of others. Self-help groups can create a space, where qualitative data is gathered and experiential knowledge is created, which gave the necessary impulsion for the intersex movement to be launched in the 1990s, as the analysis shows. While this is not exclusive to patient group initiatives, this kind of group is more similar to the intersex movement than other group initiatives.

HSM are defined as "collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organisations, supporters, networks of co-operation and media". (Brown & Zavestoski, 2004, p.679). Furthermore, HSMs are direct forces of opposition to the medical authority and its political power. Zola argued in 1972 that medicine is an institution of social control; it is, therefore, foreseeable that movements engage to change medicine, just like any social movement aims to change a social order. Brown and Zavestoski (2004) explain that there are different reasons for the emergence of HSM, such as the scientficisation of decision making and the rise of medical authority. Alongside with EBM, the first ensures that policies remain objective and scientific. While taking into consideration the participation of the public, the scientficisation of decision making uplifts the expert's knowledge. Regarding the medical authority, HSM create "a formal and institutionalised opposition" (Brown & Zavestoski, 2004, p.682) to the medical power previously exposed. The authors claim that there are three types of HSM; health access movements, embodied health movements and constituency-based health movements. This research focuses on the second one, which Brown & Zavestoski (2004) defines as groups that "address diseases, disability or illness experiences by challenging science on aetiology, diagnosis, treatment and prevention. [They include] 'contested illnesses' that are either unexplained by current medical knowledge or have environmental explanations that are often disputed" (p. 685). In an article published in Health Expectations in 2008, Charlotte Williamson writes that there are seven lines of evidence for a radical patient activist group challenging the dominant interest holders, and changing the status quo. She uses the term patient movement to refer to "patient groups, individual patients and patient representatives, advocates or activists who want to improve health-care for the sake of other patients"

(Williamson, 2008, p. 102). As her definition is similar to the definition of HSM, this research uses HSM. The seven lines Williamson (2008) identifies are:

1. **Radicalisation of activists**: radicalisation consists of the realisation that a treatment is threatening the persons' ability to be perceived as competent, rational and knowledgeable. This discovery comes from personal experiences, shared experiences or intellectual/moral convictions. For radicalisation to occur, the fulfilment of three conditions is necessary:
    a. A realisation that the treatment the patient has experienced is or was harmful to themselves or outlines a potential threat to other patients,
    b. A feeling that the treatment was in opposition to the persons' moral identity, as the risk and harm was not (entirely) disclosed. The possibility to take an informed decision regarding the treatment is whished and,
    c. A discovery that protests regarding the treatment were later disregarded.
2. **Creation of new knowledge**: consists of the realisation that an issue must be addressed with an argumentation based on evidence. Knowledge comes from personal and collective "experiences, knowledge, intuitions and perceptions" (Williamson, 2008, p. 106). Familiarity with professionals and medical knowledge can either make activists more compliant with medical values or, and just as likely, have the opposite effect.
3. **Identification of guiding principles**: HSM use different principles to judge standards of care as good or bad. Williamson (2008) defines these principles as "something that gives patients the most personal experience of health-care, often determining its clinical outcome and always affecting patients' judgement of that care" (p. 104). The guiding principles could encompass: respect, choice, information, equity, representation or shared-decision making and tend to contribute directly or indirectly to the autonomy of the patient.
4. **Sense of direction**: HSM judge the proposed changes in policies or standards of care. These changes are usually perceived as positive if they participate in the autonomy of the patient and shared-decision making.
5. **Ability to unmask new issues**: Through the new knowledge raised by HSM in step 2 and the sense of direction in step 4, HSM are in the capacity to identify potential harms or threats in new policies and proposed standards.
6. **Schism inside the movement**: HSM are often seen as emancipatory movements, and it is common to find opposition within them. Opposition usually appears for

strategic concerns, a competition for resources or between radical and conservative individuals or groups.

7. **Allies outside the movement**: HSM find allies since the 1950s in different medical professionals, who can give technical advice, alert the movement in case information is hidden from them or explain the resistance of certain professionals to higher/better standards.

Williamson (2008) writes that sometimes information is deliberately restrained from patients and the public. This phenomenon can be coercive if patients would not have made the same decision would they have had the information, but always is, if the information the patient is not receiving affects their lives. Social movements often use the same principles from one another. For example, justice and equality, which were some of the guiding principles of the women's liberation movement, the civil rights or the queer movement. HSM tend not to use these values as principles, possibly due to immaturity of the movement. Williamson (2008) argues that patients seeking equality is a "weak group's politically apt approach to a strong group that can coerce or oppress it, but whose skills and good-will it needs" (p. 107).

To conclude, there are different types of social movements that share the commonality to mobilise for or against a change. Social movements can be found within medical institution. In that case, they engage for changes in the standards of care. The following part conceptualises one way social movements engage for their cause, namely the international human rights law system.

1.3.2. Living rights, social justice and translation of children's rights

The previous chapter explained that social movements were organising for or against a change of a social or medical order. There are different types of social movements and political mobilisation is the one this research is the most interested in. This chapter is going to argue that political mobilisation can occur by using the international human rights law system and its regional or international forms. It is going to first define international human rights, second contextualise its institutions and finally explain the translation process to social justice. These theories are essential to analyse the intersex movement, and the strategy it follows since approximatively 2010.

Even if social movements need strong expertise to use human rights mechanisms, these are surprisingly open to seemingly powerless groups. Human rights can be beneficial for discursive, political and strategic practices. There are three utilities for social movements to engage with human rights systems claim Merry, Peggy, Rosen and Yoon (2010): As a system of law, a set of values and a vision of good governance.

Merry et al. (2010) define the system of law as the sum of "multilateral conventions or treaties binding on those countries that ratify them" (p. 106). Human rights as a system of law, might be found at an international or a regional level. Thus, it encompasses the United Nations (UN) and the possibility to bring complaints to treaty bodies (Merry et al., 2010); such as, amongst other, the Convention on the Rights of the Child (CRC), the Convention against all Forms of Discriminations Against Women (CEDAW) or the Convention against Torture (CAT) (*Monitoring the core international human rights treaties*, n.d.). At a regional level, different bodies exist that hear complaints and take decisions (Merry et al., 2010). For instance, the Inter-American Human Rights Commission or the Council of Europe.

Human rights centre around the values of "human dignity, equality, non-discrimination, protection of bodily integrity from state violence as well as other forms of violence, and freedom" (Merry et al., 2010, p.107). They have a purpose of being universal, thus applying to each and every human on the planet. The universality of the principles is legitimated by the fact that they represent some international consensus (Merry et al., 2010). Karl Hanson and Olga Nieuwenhuys (2013) write in the introductory chapter of their book *Recontextualising children's rights in international development*, that the CRC recognises rights to children in all parts of the world and "not only in the wealthier part" (p.3). The authors further explain that the convention and the rights accorded to children come from a process of legal negotiation that lasted ten years. Continuing by stating that children's rights are "an imperfect compromise negotiated at a certain moment in time and in specific contexts by individuals representing different local organizational interests and possessing different kinds of knowledge, skills and powers" (p.10). The core principles of children's rights, also referred to as general principles, are non-discrimination (art. 2 CRC), the best interest of the child (Art. 3 CRC), survival and development (Art. 6 CRC) and finally the right to be heard (Art. 12 CRC). For many actors in the field of children's rights, participation rights, which include the right to be heard, are perceived as the most revolutionary aspect of the CRC, as they place the child as an actor in regards to their own rights (Hanson & Vandaele, 2013). While participatory rights are usually seen as essential for children's rights, even if the feasibility is sometimes questioned, other guiding principles are being criticised by scholars (Hanson & Lundy, 2017).

Finally, the last way human rights can be utilised by social movements according to Merry et al. (2010) is governance. This is at the crossroad of human rights, development and democracy. Human rights are not politically neutral, but "a mode of governance that upholds human rights" (p. 107). In that sense, human rights (and children's rights) are adaptable, evolving over time through interaction, discussion and the unpacking of new social issues. Social movements use the human rights system in a process that Merry et al. (2010) call vernacularisation or Hanson and Nieuwenhuys (2013) name translation. The authors speak about living rights, meaning that social movements can shape existing and codified rights to a social world.

Living rights move toward social justice, which arises from the moral economy, consisting of a circular relationship between social movements and communities having issues (Hanson, Nieuwenhuys, 2013). These problems include a multiplicity of areas for which the state is the primary guarantor of access such as: resources including land, water and employment or services like health, education and access to food. Social movements use the tools offered by the state to bring a claim forward and reach social justice. Gregg Barak defines social justice as "part of the ongoing struggles against the repression of any people and on behalf of the liberation of all people" (Barak, 2015, p. 392). Therefore, social justice pursues the goal to act against repression, defined as "any action by another group which raises the contender's cost of collective action" (Tilly, 1978, p. 100).

Finally, the concept of translation is what binds living rights and social justice together and is "about what happens with rights in the encounter of children's and other actors' perspectives, movements for social justice and the elites, authorities and opponents" (Hanson & Nieuwenhuys, 2013, p. 16). I'Anson, Quennerstedt and Robinson (2017) see translation as a multi-stepped process, that goes from implementation from a convention in national legislation and in professional reports. The authors claim that "professional ethical accountability is produced through this translation process, whilst professional responsibility is discharged through the reporting process" (p. 60). Thus, social movements use the international system of law to bring rights alive. Social movements articulate their claims on defined sets of values to translate or vernacularize the rights into concrete policies and national legistlations. The process of translation is not a linear, monolithic process but uses political opportunities, alliance-building and other social movement’s strategies. The fact that rights can be re-interpreted over time, to adapt themselves to new socio-economic and juridical contexts gives social movements, non-governmental organisations and other stakeholders means to uplift their cause and make it recognised as a human rights issue.

1.3.3. Expertise and experience: political subjectivity and epistemic injustice

Previously, the capability of actors to politically engage and influence a social change was addressed. It also mentioned the existing power asymmetries when doing so.

Hereafter, the political theory of Miranda Fricker (2007) on epistemic injustice will be explained, with the objective to highlight what causes asymmetrical relationships. This concept will be useful in the analysis of this paper as some traits, of the intersex movement and of its opponents, make the credibility of the claims asymmetrical. The chapter will first explain political subjectivity and then the two types of epistemic injustice: testimonial and hermeneutical injustice.

According to Foucault (1982), subjectivity has a double meaning: being the subject to someone's control, and an identity constituted by self-knowledge. Thus, the construction of the subjectivity is shaped by a variety of discourses, articulated according to social structures and practices (Niesche, 2013). For Gaulejac, writes Charlebois (2017), the subject has to be first a social, then an existential and lastly a reflective subject to engage in politicisation and become a subject-agent. In that sense, a subject ought to go through a process before being a political subject. Häkli and Kallio (2018) argue that there is a circular relationship between political subjectivity and political agency; political subjectivity arises from but also constitutes the agency. For a person to become an agent and therefore influence social structures, the individual needs to have access to information to reflect on personal subjectivity. Furthermore, the person's testimony has to be considered with enough credibility. Building upon Charlebois' (2017) work, political subjectification is a challenging process for oppressed groups, such as people with a VSC. In the analysis part of this master's thesis, cases of epistemic injustice within the intersex movement and the relationship of the movement to the medical institution are analysed. Previously, power was defined as a continuum of war, resulting in a dynamic relationship between actors. When Miranda Fricker (2007) writes about power, she addresses the concept of social power; the capacity to influence the functioning of a social world by social agents. It is essential to note that social agents are not only individuals but also groups of people or institutions. Power, according to Fricker (2007), can operate actively or passively. It operates actively when a person has the authority to punish someone else for their action, and passively when someone's behaviour changes as a result of the power status another person has. The latter is in opposition with a Foucauldian notion of power that only exists "when it is put into action (Foucault, 1982, p. 219)" (Fricker, 2007, p. 10). Furthermore, Fricker (2007) conceptualises identity power; a special power a person obtains because of its status for example, being a cisgender man, white, heterosexual or able-bodied.

Fricker (2007) introduces two distinctive types of epistemic injustice, emerging from actively or passively expressional social and identity power, testimonial injustice and hermeneutical injustice. According to Fricker (2007), epistemic injustice is "a kind of injustice in which someone is wronged specifically in [their] capacity as a knower" (p. 20). Epistemic coming from ancient Greek meaning knowledge, this injustice marginalises a person as a subject of knowledge. Hereafter, testimonial and hermeneutical injustice will be defined.

Testimonial injustice finds a home when the credibility of a person's testimony is given more or less credibility than deserved. Wanderer (2017) defines a testimony as "an internally diverse pattern of norm-governed interactions that includes the speech act of telling someone something close to its explanatory centre" (p. 27). Fricker (2007) argues that the credibility accorded to a testimony can be found in excess or in deficit. Many different features can contribute to one speaker's knowledge being considered as more or less credible; amongst others, a persons' accent, gender, profession (Fricker, 2007) and abilities (Hayes and Hannold, 2007). Meaning that the credibility accorded to the discourse of a person is based on stereotypes and pre-judgement.

Hermeneutical injustice is defined as a situation in which "a gap in collective interpretive resources puts someone at an unfair advantage when it comes to making sense of their social experience" (Fricker, 2007, p.1). Medina (2017) defines it as when a person encounters unfair obstacles in making sense of their own story. These obstacles occur in different forms, as Fricker (2017) explains. Furthermore, she writes that feminists had to break the silence to speak out about the "this" that had no name. In the process of sharing, a collective narrative can be created, and a person might access keys to knowledge. However, the lack of access to information hits groups differently, sometimes to the point of hermeneutical death. While methods exist to reduce the marginalisation, epistemic injustice has a strong effect on the degree and shape of agency a social actor has. In some cases, injustice is persistence and systematism of the injustice is such, that it has long terms effects (Simpson, 2017).

The concepts of political subjectivity and epistemic injustice will be crucial to understand the evolution and trajectory of the intersex movement. This research believes that reaching epistemic justice is essential to achieve epistemic diversity and objectivity on any topic or social issue. Pushing marginalised voices forward, does not mean giving them all the credibility but them as equally important knowers than those who, due to stereotypes, get excessive credibility.

Chapter 2. Research problem

"The surgery of the hermaphrodite has remained terra incognito" (Young, 1937 cited by Chase, 2002, p. 129) wrote Dr Young, urologist at John Hopkins hospital in the USA in 1937. With the democratisation of new techniques of care, such as anaesthesia, he saw potential for a "great variety of surgical procedures" (Young, 1937 cited by Chase, 2002a, p. 129). After first engaging in research by himself, a multidisciplinary team was formed at the beginning of the 1950s, creating the first medical recommendations for children with a VSC (Karkazis, 2008). From then on, multiple articles were published explaining the theory. For instance, in an article written by Hampson, Money and Hampson in 1955 five recommendations were outlined (Hampson, Money, Hampson, 1955), and briefly summarised below:

1. **Sex assignment**: Sex should be assigned after sufficient investigations to reduce the risk of a reassignment at a later point, but as soon as possible.
2. **Sex reassignment**: "Safe" sex reassignment is only possible if the gender role of the child is not developed. Before 18 months, there is no problem with reassignment, yet after 2.5 years of age, it was believed that gender role is established in the child and therefore changing their sex was going to leave psychological sequels and should be done under supervision. The team defines gender role as what the child "learns, assimilates and interprets" (Money, 1955, p.265) from interactions with the environment as well as personal reading of their own body.
3. **Surgery**: Surgeries should happen as early as surgically safe.
4. **Parental support**: The family medical advisor is responsible for dealing and responding to perplexities and uncertainties of parents using the concept of unfinished genitalia, which was preferred as it did not refer to a state of ambiguity. Moreover, emphasis is placed on reinsuring the parents that the child can grow up as healthy as any other child and that they will be able to have a (heterosexual) marriage.
5. **Patient information**: When old enough, the person with a VSC should receive an explanation about their condition using the concept of unfinished genitalia. The explanation should mention that the operation(s) was or were aiming to protect them from their playmate's sexual curiosity.

These recommendations illustrate a paternalistic approach of care. Medical practitioners were the only ones deciding about the medical treatment (Schein, 1980, p. 1036) as they were the source of knowledge. Furthermore, information had to be kept from the child and their parent. In some cases, conferences were organised to discuss the management of particular cases. An article published in 1954 in the Journal of Urology *True Hermaphroditism: A Conference on the Management of one patient* illustrates this clearly, as neither the parents nor the 14 years old child were invited to participate in the decision-making process concerning the possibility of sex reassignment, operations and hormonal treatments (Marshall, 1954). At the root of the paternalistic model featured by these five recommendations forming the John Hopkins Paradigm, was the assumption that new-borns are psychosocially neutral. Meaning that gender identity is not inherent to the person. Identity develops from the gender of rearing and body image (Alm, 2008). This, and the lack of techniques in surgeries to operate on genitals to make them fit expectations of male genitals (Karkazis, 2008) are potential explanation for the assignment of 96% of children with a VSC to a female sex (Dreger, 1999 cited by Hausman, 2000). Dr John Gearhart's statement illustrates this claim as, in his words, "it is easier to make a hole than build a pole" (Dr John Gearhart, quoted by Holmes, 2000, p. 101).

With the development of the internet, an intersex movement started to emerge in the 1990s (Karkazis, 2008). These new technologies, enabled the first generation of children who had undergone "normalising treatments", to discuss, connect and realise that they were not alone (Chase, 2002a). As strong emphasis on secrecy and misinformation was put in the first standards of care, the internet and the movement helped members access to information about their bodies, treatments and the politics around them. Cheryl Chase, who now goes under the name of Bo Laurent, was the founder of ISNA, the largest intersex advocacy group at the time (Chase, 2002a; Davis, 2015). ISNA was aiming to "build a world free of shame, secrecy and unwanted sexual surgeries" (see www.isna.org).

After years of organising protests and support groups, ISNA changed strategy and started to actively work within the medical establishment to change the practice from the inside. ISNA's advocacy peaked and came to an end two years after the release of the Consensus statement in 2006, which was drafted during an International Consensus conference on intersex in Chicago in 2005 (Merrick, 2019). The Consensus group, composed of 48 specialists amongst which two intersex advocates, 19 endocrinologists, nine urologists, and ten psychologists (Hughes & all, 2006) recognised a need for change induced by "progress in diagnosis, surgical techniques, understanding of psychosocial issues, and recognising and accepting the place of patient advocacy" (Hughes & all, 2006, p. 554). David Reimer served as an example for Money's nurture theory, as after being subjected to a disastrously failed circumcision, was raised “as a girl”. However, in 1997, Rolling Stones Magazine mediatised his case and reported that the operation and treatment failed as he lived as a boy. While not being born with a VSC, his case highlighted the necessity for change in standards of care and that Money’s concept on gender being nurtured was not based on evidence despite his claims (Colapinto, 1997, The Associated Press, 2004).

In 2006, the Lawson Wilkins Pediatric Endocrine Society and the European Society of Pediatric Endocrinology published the Consensus statement (Hughes, Houk, Ahmed & al, 2006, p.1), which became the new international standard of care. The main changes suggested the need for a multidisciplinary team to take care of children with a VSC, open communication with the parents of the child and psychosocial care. With the Consensus statement, the model of care has been revised to meet new contemporary standards and shifted from a paternalistic to a patient-centred model. It also aimed to develop a shared decision-making process, where parents should be involved, especially when the decision is challenging (Karkazis, Tamara-matis, Kon, 2010, see also ISNA, 2008). What makes these decisions challenging is the lack of evidence-based knowledge. Therefore, the Consensus group also calls for studies on the long-term outcomes, surgical outcomes, risks of gonadal tumours as well studies on cultural and social factors, which were inexistent. As Karkazis et al. (2010) suggest, healthcare providers made recommendations based on their experience in practice, personal values and gut feeling. While the Consensus statement was in various regards an advancement for the intersex movement, as it was the first medical conference where intersex advocates were present (Karkazis, 2015, Thomas, 2007), it was also the source of a controversy that reverberates today. This controversy relates to the DSD terminology, an umbrella regrouping various syndromes.

Until the Consensus statement and associated the research, only the Human Rights Commission of the City of San Francisco had ever released a statement on intersex human rights (HRCSF, 2005) and few groups framed standards of care imposed to children with a VSC as a human rights issue. AGGPG is an example of one of these groups, having already framed intersex operations in Germany as genital mutilations and the medical practice as serious human rights violations (Reiter, 1998). Two years before the conference, the Organisation Internationale des Intersexués (OII), an international network for intersex advocates, was founded. OII’s advocacy was in greater opposition to the medical establishment than ISNA and other organisations that existed at the time (Davis, 2015). It was formed as a network of regional organisations such as OII Australia (hereafter referred to as Intersex Human Rights

Australia (IHRA)), OII Francophonie, OII Chinese or OII USA. Since its beginning, OII was speaking against the Consensus statement, the new terminology and ISNA's support to the DSD terminology. The network argued that their bodies were not disorders that should be ordered (Curtis, 2007). Even if AGGPG framed intersex as a human rights issue, its impact was national and restricted to the German context. This research focuses on the emergence of a global IHRM, a process that started once AGGPG was defunct, therefore this organisation will not be further analysed.

One decade after the Consensus statement, an IHRM was formed and successfully institutionalised intersex issues within international and regional human right institutions. As Crocetti et al. (2020) mention, the IHRM has been working with different human rights frameworks such as:

1. Harmful practices
2. Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
3. Integrity of the person
4. Access to justice
5. Involuntary medical experimentation
6. Violence against children
7. Right to life
8. Coercive sterilisation
9. Right to health
10. Rights of the Child
11. Anti-discrimination laws that include sex

Considering the relative recency of intersex advocacy, this paper aims to understand how the movement changed the way it engages for the protection of children with a VSC from medical harmful practices. Through the analysis of the controversy between ISNA and OII in the beginning of the 2000s, it will contextualise the globalisation and professionalisation of the intersex movement from 2005 to 2015 to finally respond to the question respond: How did the Consensus statement participate in the emergence of an international intersex human rights movement?

Chapter 3. Methodology

3.1. Interdisciplinary qualitative research

Regarding the scope of this research and the aim to understand how the global IHRM was emerging, it seems that a qualitative research method is the most adequate. Instead of using quantitative data, this paper pursues the objective of an in-depth understanding of the intersex movement, its challenges and narratives. Therefore, words are preferred to numerical data (Poretti, 2019). To understand the emergence of an intersex movement, problem-centred interviews were conducted with ten intersex advocates and one policymaker. This type of interview "aims to gather objective evidence on human behaviour as well as on subjective perceptions and ways of processing social reality" (Witzel, 2010). Witzel and Reiter (2012) argue that the researcher who wants to conduct problem-centred interviews must take the role of a "well-informed traveller". The authors see the researcher as a traveller who embarks on a journey with expectations and obtains additional information during their trip (or research) in the communication with the people met along the way. To embark on this research, information has been retrieved from secondary sources of information and archives that could be found on the internet, in books and organisational archives sent by interviewees. The review of the existing literature and knowledge was used to answer questions that did not need insight from the problem-centred interviews or to contextualise the information retrieved. Following Witzel and Reither (2012) theory, the orientation, assumption and expectations of this research has been evolving. The dialogue with actors in the field have highlighted new problematics and events. These continuously reshaped the research and analysis. Witzel (2010) claims that four instruments exist to support the interviewer in accessing information;

1. a short questionnaire to gather some basic social characteristics
2. an interview guideline to give a framework of orientation and facilitate the comparison between the interviewees
3. Recoding the interview
4. Transcriptions

Furthermore, Witzel (2010) recommends that the transcriptions not only include what was being said but also non-verbal communication forms; such as laughter, pauses and hesitations. This should bring a more in-depth understanding of the narratives and challenges the participants faced.

Additionally, the research was designed to be interdisciplinary, applying concepts from the fields of history, sociology and politics. More than being a "trendy" term in research, interdisciplinarity is a core value in this research. Interdisciplinary is fundamental in intersex studies as intersex realities are in a tension between medical, legal, and social perceptions. Darbelley (2014) argues that interdisciplinarity is more than simply juxtaposing different disciplines, it is about making them interconnect and interact, to understand how they impact each other. By making use of various concepts coming from different field in social studies and law, this paper aspires to be interdisciplinary.

3.2. Ethical considerations

All research must take ethical considerations to guarantee the requirements for integrity in the search for the truth (Geneva Institutions of Higher Education, 2019). The relative recency of the IHRM and the small number of intersex voices that speak out in 2020 could be reflections of the stigmatisation the community faces. Therefore, strong ethical considerations have been taken. These considerations are going to be explained and illustrated with statements from the intersex interviewees, whose voices have been integrated throughout the research design. These considerations consist of consent, anonymisation and language but utmost care was also given to reduce the risk of instrumentalisation and reach a state of epistemic justice.

1. **Informed consent**: informed consent is at the core of any ethical consideration. Participants must know about the scope of the research, that they can always decide not to answer a question or decide to stop their participation. In the case of this research, all participants were informed via e-mail and at the beginning of the interview, that this paper is destined to obtain a master's degree in interdisciplinary children's rights studies.
2. **Anonymity**: all participants had the possibility to be anonymised for this research. An anonymisation protocol was designed, which included the usage of gender-neutral pronouns, the avoidance to mention the country of residence or activism and the usage of a fictive name. However, all participants agreed to be named with their legal or preferred name. Daniela Truffer (personal conversation, 8. May 2020), a representative of Zwischengeschlecht.org/StopIGM.org (hereafter StopIGM.org) explained that she had issues with researchers and scientific projects anonymising her and using her as a test subject. According to her, this makes history repeat itself. Considering that all interviewees are public figures in the movement, and that more often than not, are amongst the most vocal voices in their region, anonymisation did not make much sense for them. Moreover, naming the

people cited is a way to portray the participants as knowers, a step towards epistemic justice and diversity.

3. **Do no harm**: this research does not aim to cause any harm to the intersex movement or interviewees. Therefore, and especially since participants are not anonymised, all participants received the quotes used and transcription one month before deadline; with the exception of one participant who formally asked that it is not shared with them. To avoid sending quotes from other participants that might need to be changed, only personal quotes were sent. Sharing the statements before-hand is also important as it reduces the risk that the words are being taken out of their context. Dan Christian Ghattas (Personal communication, 29. April 2020) requested a copy of the transcriptions for his historical archives, although this was not specifically stipulated by each participant, all received them at the same time as the personal quotes.
4. **Language**: this research showed the importance of language in the context of intersex advocacy and healthcare. Consequently, particular care has been taken to use the language the interviewee feels most comfortable with, whether it is DSD, VSC, intersex, hermaphrodite or something else. In general, human rights predominant terminologies were used but when historically or contextually relevant, other terminologies were employed.
5. **Gendering**: In accordance with the research topic, no presumptions on sex and gender will be made. This goes is in line with the Code of ethics and professional conduct for the Geneva institutions of higher education (Geneva institutions of higher education, 2019), which claims that no discrimination based on sex and gender should be made. Therefore, all participants will be asked about their pronouns, whether female, male, non-binary or none. The 7th edition of the Manual of American Psychological Association (APA) endorses the usage of singular they to address people whose gender is unknown or irrelevant as well as when this is the coherent pronouns to a person's identity (*Welcome singular "they"*, 2019). While using the 6th edition of the APA, this particularity of the 7th edition will be used as in line with the ethical considerations and theme of this research.

3.3. Personal bias and epistemic credibility

As mentioned, I am an intersex person and an advocate. This paper is, therefore, a personal and intellectual challenge for me. Nevertheless, I believe that thanks to my experience and intersex network, I will be able to tackle the research with more sensitivity than other might. After reading a variety of stories of academics and activists and talking with some of them, I realised I had to find ways, like Caldéron (2004) writes, to combine my "research objectives without losing my commitment to progressive social change" (p. 81). To guarantee the most objectivity possible, I took particular care not to intervene during the interviews with people who may have had different political positions than mine, to always look at the data with some distance and to not let my feelings and ambitions take the lead. I committed to the same scientific discipline than fellow students, comrades and researchers. However, I am aware that I might stumble across some criticism from academics, finding my work too politically oriented. While this presupposition is understandable, authors mentioned in the theoretical part, such as Foucault, maintain that all knowledge is socially constructed and never neutral. Furthermore, some groups receive more credibility for their contribution and knowledge (Fricker, 2007). For instance, medical professionals can claim not having conflicts of interests with the article they publish, despite having financial, moral or scientific stakes. Intersex researchers in the field of intersex studies shared their experience in articles or blog posts. Georgiann Davis warned me the stigma or being an intersex researcher in intersex studies. Davis said:

> If you are talking about your experience with intersex, I warn you, that people in an academic setting will say that she's biased. You can say 'I love doctors' or 'I hate them' or something in between, they will always say that you are biased. (G. Davis, Personal communication, 20. April 2020)

In the article called *Can Intersex subjects reflect (upon themselves)?* Janik Bastien Charlebois (2017) questions a multiplicity of restraining factors that intersex researchers might encounter when engaging in the process of political subjectification. In another article, Bastien Charlebois (2016) claims that having access to academic tools and academic discipline does not bring more credibility to the words of an intersex researcher because of dominant cultures, such as the medical establishment perceiving intersex voices as "raw, emotional and not specialised" (Bastien Charlebois, 2016), or academic culture.

3.4. Research sample

The research sample consists of 11 persons from Europe, North and South of America and Oceania. All interviewees have played an essential role in the emergence of the intersex movement, whether it was by being one of the leading voices of ISNA, being part of the OII network, by creating a highly visited online forum, or by focusing on advocacy at the UN. One interviewee has influenced the movement by working for an international Lesbian, Gay, Bisexual, Trans and Intersex (LGBTI) organisation as a policy officer.

Name	Pronouns	Date	Country	Organisation(s) 2006 - 2015
Alice Dreger	She/Her	23.04.20	USA	ISNA
Betsy Driver	She/her	26.04.20	USA	Bodies Like Ours
Curtis Hinkle	He/Him	18.04.20	USA	OII International
Daniela Truffer Markus Bauer	She/her He/Him	08.05.20	CH	Zwischengeschlecht.org StopIGM.org
Dan Christian Ghattas	He/Him	29.04.20	DE	TransInterQueer (TrIQ) IVIM / OII Germany OII Europe
Georgiann Davis	She/her	20.04.20	USA	University of Nevada
Ins A. Kromminga	They/them	21.05.20	DE	IVIM / OII Germany
Kris Günter	He/Him	21.04.20	BE	Genres Pluriels OII Belgium
Mauro Cabral	He/Him	04.06.20	AR	GATE
Morgan Carpenter	He/Him	23.04.20	AU	OII Australia (name change to IHRA)
Silvan Agius	He/Him	30.05.20	BE MA	ILGA-Europe Government of Malta

Chapter 4. Presentation and analysis of the results

4.1. From "Hermaphrodites with Attitude" to the Consensus statement

4.1.1. ISNA: A radical patient group?

Cheryl Chase, who now goes under the name of Bo Laurent, is the founder of ISNA; an association that was amongst the first ones to group people with all VSC, instead of specific "diagnosis". After telling their personal story and founding ISNA in 1993, Laurent received letters from intersex people from North America and Europe. These stories and testimonies gave Laurent a picture of the psychological consequences of surgical interventions in childhood, that were all coherent (Chase, 1998). As one of the first organisation opposing the medical standards of care regarding intersex variations, ISNA faced different struggles, deceptions and victories, making the organisation's strategy change. Looking at the theory on social movements, it is arguable that ISNA was an HSM, as it aimed to change the medical practice and standards of care. Williamson (2008) explains that there tends to be two types of patient movement or HSM, radical and conservative ones. She also claims that a group might change positions, strategic approach, especially regarding the collaboration with medical professionals. Building upon Williamson's (2008) work, this chapter is going to contextualise the beginning of intersex advocacy as an HSM and illustrates how the familiarisation with medical professionals and knowledge changed the organisation's trajectory. Williamson (2008) developed seven lines to understand HSM, around which this analysis will articulate.

1. **Radicalisation of activists**: Williamson (2008) outlined three conditions for the radicalisation of patient groups. First, with the reception of letters and discovery of various different testimonies, Laurent and other ISNA intersex members realised that the medical care they received as a child was harmful; psychologically, physically and sexually. Thus, and with the understanding that this practice still was a threat for the future and present generations of children born with a VSC, Laurent had the urge to make a change. In that sense, the first condition for radicalisation is fulfilled. Secondly, ISNA members felt that the treatments received were in opposition to their moral identity and that the harm, they suffered from, was not fully disclosed before-hand. This point is particularly important in the radicalisation of the first people in the movement

as secrecy was a central part of the John Hopkins Paradigm. With that in mind, Laurent wrote in an article that medicine received the authority or power to police the sex dichotomy, leaving people with a VSC "to recover the best they can, alone and silent, from violent normalization" (Chase, 2002a, p.193). The members of the organisation wish to have been able to make an informed decision regarding the treatment received, and consequently meeting the second condition. The third condition is that protests regarding the treatments were disregarded. This condition is also satisfied as Laurent states that for some of the children victim of the medical treatments, the surgeries end only when the child has grown old enough to resist (Chase, 2002a). ISNA was a radical movement empowering activists to change the medical practice by joining experiences (Chase, 2002a).

2. **Creation of new knowledge**: The Foucauldian concept of knowledge-power, claimed that knowledge is conditioned by the dominant power forces, but also uprises the power or domination groups receive (Foucautl, 1976/1978). As ISNA was opposing one the most powerful institution, it needed to gather evidence and create knowledge, attesting the harm of the medical procedures done on children with a VSC. According to Epstein (2007), this knowledge can be acquired qualitatively from discussions in self-help groups and the creation of a collective narrative, but also by engaging in research. One of ISNA's short term goal was "to create a community of intersex people who could provide peer support to deal with shame, stigma, grief and rage" (Chase, 1998, p.197) also to get medical documents. ISNA aimed to transform "personal experiences of violation into collective opposition to the medical regulation of bodies" (Chase, 2002a, p.131). In creating a network, evidence could be gathered to opposed claims such as: "not one patient has complained of loss of sensation, even when the entire clitoris was removed [...] the clitoris is clearly not necessary for pleasure" (Edgerton, 1993, p. 956). According to ISNA, intersex surgeries are processes that destroy the person (Chase, 2002a). With the newsletter *Hermaphrodites with Attitude*, ISNA aimed "to provide a counterpoint to the mountains of medical literature that neglect intersex experiences and to begin completing an ethnographic account of that experience" (Chase, 1998, p. 198). It is safe to claim that ISNA's ambition was to participate in the creation of epistemic resources, fulfilling Williamson's (2008) second line.
3. **Identification of guiding principles**: Any movement follows some guiding principles, claims Williamson (2008). These give a trajectory to the organisation's

work. From a preparatory article for the *First World Congress: hormonal and genetic basis of sexual differentiation*, it seems that ISNA's guiding principles were choice, information and shared-decision making. Writing that "the child is the patient, not the parent" (Chase, 2002b, p.2) and "honest, complete disclosure is good medicine" (Chase, 2002b, p.2), the organisation clearly marks that it pursues the objective that the patient participates, after having accessed all relevant information regarding the risks and options, to the decision-making process.

4. **Sense of direction**: What ISNA is advocating for is a gender assignment (male/female) to any child, but without unnecessary surgeries. Only this position will prevent irreversible physical damage and respect "the intersex person's agency regarding his/her own flesh" (Chase, 1998, p. 198). As this position is in clear opposition to the medical guidelines claiming that gender identity is nurtured, and that the appearance of the sex should be in line with the sex of rearing (Hampson, Money, Hampson, 1955), ISNA's position was considered as revolutionary.

Williamson (2008) outlines three additional lines for HSM or patient groups; ability to unmask new issues, schism inside the movement and allies outside the movement. These lines entail ideas of opposition and controversies. Therefore, they will be discussed when analysing the Consensus statement and the creation of the international OII network.

4.1.2. The conservatisation of intersex advocacy

Since its beginning, the main goal of ISNA was to change the medical practice to protect the future generations of children with a VSC from medical harm. During the first years of the organisations' existence, ISNA pursued a confrontational strategy, organising protests in front of hospitals or medical conventions, such as the annual meeting of the American Academy of Paediatrics in 1996 (Chase, 1998; Chase, 2002a). The organisation used the word hermaphrodite as emancipatory, releasing newsletters under the name *Hermaphrodites with Attitude*. However, the ISNA's efforts to dialogue stayed unheard and even ridiculed by doctors, dismissing its demands, or calling the group zealots. After the 1996 protest, the American Academics of Pediatrics published a press release claiming that:

> The Academy is deeply concerned about the emotional, cognitive and body image development of intersexuals, and believes that successful early genital

> surgery minimizes these issues […] From the viewpoint of emotional development, 6 weeks to 15 months seems the optimal period for genital surgery. (News Release: American Academy of Pediatrics Position on Intersexuality, 1996)

A statement that disregarded the political demands of the association altogether. Alice Dreger (Personal communication, 23. April 2020), one of ISNA's leading voices since the early 2000s, argues that the LGBT rights movement profoundly influenced the organisation, inspiring it to pursue a confrontational approach. This could be a reason why the claims and demands were not heard. Over time, however, doctors started to agree with the organisation, which wanted to absorb their voices. ISNA saw in medical allies an opportunity to increase the legitimacy of its demands in the eyes of the medical establishment. Building alliances with people outside the movement to increase legitimacy is also one aspect of HSM (Williamson, 2008). This has always been part of ISNA's strategy, which joined the LGBT, feminist and civil rights movements in its beginnings. Laurent claims that these alliances helped members to speak out and to politicise intersex issues (Chase, 1998; Chase, 2002a). However, by absorbing the medical voices that agreed with the ISNA's position, the association's strategy changed and became less confrontational. Being more involved with medical literature and practitioners is a double-edged sword for HSM, claims Williamson (2008), as members either get more radical or more conservative. Also, Williamson (2008) argues that alliances with medical professionals can give the HSM technical advice, alert the movement in case information is hidden from them or explain the resistance amongst professionals to change their practice. Dreger (Personal communication, 23. April 2020) remembers reading an article from an ally doctor mainting that ISNA should not have an extreme approach to advocacy but that a third way should be advocated for. They recommended that while all children should be assigned a gender, genitals should remain untouched. Dreger remembers being in shock when reading this, as this was exactly what ISNA was advocating for. She took it as a proof that the medical professionals did not bother looking at ISNA's position. Based on presuppositions about the movement, the claims and testimonies were not given enough credit. With that statement but also other similar experiences, ISNA unmasked issues satisfying another line for HSM. One of the issues that was unmasked, regarded the term intersex, believed ISNA. Dreger (Personal communication, 23. April 2020) argued that the term was too politicised for medical professionals to use it. Intersex was being used by LGBT or feminist movements and often perceived as a gender identity, when it is not. Despite ISNA trying to have a dialogue with medical professionals, they would not understand that intersex was used as an umbrella term for many variations. When in discussion with medical professionals, these would keep arguing that ISNA speaks about intersex, but they speak about congenital adrenal hyperplasia, androgen insensitivity syndrome or hypospadias. Similarly to other HSM, ISNA's discourse was not heard, the knowledge intersex activists acquired was marginalised, or perceived as anecdotal. Betsy Driver (Personal communication, 26. April 2020), who organised and participated in a protest in 2004, was then invited by doctors to speak about intersex issues. However, she remembers the atmosphere as being condescending and having the feeling the group was perceived as freaks. Whatever she and her colleagues were saying was dismissed, as they were just the outspoken few. StopIGM.org representatives, Daniela Truffer and Markus Bauer, had similar experiences. They too organised and participated in various peaceful protests, during which they would have the opportunity to talk with doctors. However, as Truffer remembers, they were also insulted by medical professionals. Dreger, Driver, and StopIGM.org representatives found these protests draining, psychologically and physically. The latter continues to do protests in front of hospitals or medical congresses because they find it is an effective way to engage. Nonetheless, due to economical and efficiency reasons, the organisation currently allocates a majority of its resources on UN treaty body work, while still organising some protests. One of the challenges ISNA was facing was to find a way to enter in discussion with medical professionals. ISNA did not work with the law; much more the association wanted to change the hearts and souls of doctors. However, ISNA perceived two main challenges: the politicisation of the term intersex and medical knowledge being necessary to talk with doctors. In an article she published in *Bioethics in action*, Dreger (2018) writes that Bo Laurent and herself had to learn all the medical science to speak to doctors. She writes that it was common for physicians to test them on their knowledge of specific conditions and on biochemistry. Only once the tests were passed, the physicians would engage in a dialogue with the activists. Again, this points towards epistemic injustice (Fricker, 2007) as the experiential expertise was not given value. In addition to gaining enough credibility in the eyes of the doctors to engage in discussions by learning medical science, ISNA changed the terminology it used.

> As I recall, Bo and I talked, you know emailed or called a bunch of doctors and said 'what terminology would you accept?' They were already using, in some places, this terminology. And it was a question of disorder of sex differentiation or of disorder of sex development. And we were like 'which one is the most

> commonly used?' and as I recall it was 'disorders of sex development' and we were like 'fine'. Let just throw this across the wall and see if we can move them. (A. Dreger, Personal communication, 23. April 2020)

Mauro Cabral (Personal communication, 4. June 2020), who is an intersex activist in Argentina, was in touch with ISNA, and understands in retrospect the decision ISNA took. He claims that the organisation took a painful decision to change language, as it was the only one doctors were willing to hear. As ISNA wanted to participate in the creation of a conceptual framework, they hoped that using DSD would let them communicate with doctors without interference. Once ISNA changed intersex to DSD in their booklets, medical professionals would read them, which made a change. This also created a balance of extremities as Dreger (Personal communication, 23. April 2020) explains. Suddenly, ISNA could claim not being like the radical groups, with which doctors cannot work. Cabral (Personal communication, 4. June 2020) illustrates this strategy and says ISNA talked with doctors by saying "do not concentrate on them, concentrate on this and you can talk with us" and "let us talk in a very pathological way but then, the next step, which is performing the surgeries, we are going to stop at that". ISNA wanted to change language but without changing its crucial position on surgeries and unconsented and unnecessary medical treatments.

4.1.3. The consensus statement: a change in the medical paradigm?

Because "there has been progress in diagnosis, surgical techniques, understanding psychosocial issues, and recognising and accepting the place of patient advocacy" (Hughes et al., 2006, p. 554) an international medical conference was organised in Chicago in 2015. For the first time, intersex advocates were invited to a medical conference; namely Bo Laurent from the ISNA and Barbara Thomas from XY Frauen in Germany (Thomas, 2007; Karkazis, 2008). This Conference was a peak moment for ISNA's advocacy as the organisation felt that the strategy change was successful. The Consensus statement did not only recognise the role of patient advocacy, but also decided to change the medical nomenclature. Intersex or hermaphrodites, were to be changed to DSD, an umbrella term regrouping different conditions in syndromes. For the Consensus team, DSD is preferred by patients, parents and practitioners as previous terminologies were potentially perceived as pejorative (Hughes et al., 2006). Thomas (2007), wrote in an article published in *Zeitschrift für Sexualforschung* about her experience at the Chicago Conference. They argue that with DSD language, a person is not only defined as intersex, but only specific biological traits are addressed. In other words, a person is not intersex but has a DSD.

Davis (2015) explains that the new nomenclature participated in the institutionalisation of VSC in medical standards and further medicalised people with VSC. Taking over Conrad and Schneider's (1992) five step model of deviance, she applies these steps to the creation of the DSD language. She says that VSC are a deviance of the sex binary (Definition of behaviour as deviant) and that through chromosomal descriptions, the deviance/variation was discovered and announced by medical institutions. Furthermore, intersex expertise was reclaimed by medical professionals (Claims-making; medical and nonmedical interests), which created a battle over diagnosis (Legitimacy: securing medical turf) and ended with a legal recognition of abnormality (Institutionalisation of a medical deviance designation). By taking over DSD as the new officially agreed term, the Consensus statement participated in the medicalisation of intersex variations. Conrad and Schneider (1992) argue that with the institutionalisation of deviances as disorders, the new medicalisation transposes itself into medical or legal classification systems. The ICD is a perfect example of that. While VSC were already in the ICD, the terms intersex, hermaphrodite and such were replaced with DSD. This "re-inscribes the assumption of the prior treatment protocol that intersex bodies are generally unnatural and require biomedical or surgical fix resorting them to a more natural, i.e., binary, sexed and gendered way of being" (Merrick, 2019, pp. 4430-4431). That is also what Karkazis (2008) claims when writing that the medical power entails the authority to define what is natural or not. Davis (2015), argues that the Consensus statement was a way for medical establishments to reassert their authority, which was jeopardised as a result of 1990 intersex activism. With DSD, they would not fix intersex people but treat disorders. While intersex advocates were invited to the Conference in 2005 and ISNA used DSD in its advocacy, scholars such as Merrick (2019) argue that going from intersex to DSD is a case of epistemic injustice. It seems like the participation of the intersex activists was tokenised as ISNA's decision to advocate for DSD terminology was not to further institutionalise VSC but to get medical professionals to listen to their needs. This is a risk that other intersex advocates have also mentioned when working with doctors. StopIGM.org representatives (Personal communication, 8. May 2020) claimed, for example, that medical professionals sometimes use or tried to use them as a fig leaf. The organisation refuses to be used as such, which divides doctors between those who still accept to engage with the organisation, and those who do not. Thomas (2007), writes that they felt like their participation was to increase the acceptance of the Conference. Furthermore, they regret not having received the discussion topics of the Conference beforehand to discuss with fellow activists who were not invited. Also, the two intersex activists were not invited to the discussion groups regarding operations. This is pitiful as these were the most important ones for their cause. Furthermore, they write that they felt like “a wider range of opinions could have been shot in advance. The feeling remained (not only among those affected) that the meeting in Chicago was only accessible to a small arbitrarily chosen crowd[2]” (p. 192). Dreger (Personal communication, 23. April 2020) goes in the same direction and says “only two intersex people were at the entire thing. There were lots of very smart, very talented intersex people available at that point. However, they were left out”. She also explains that ISNA created a lobbying strategy for the intersex advocates and the allied medical professionals:

> “Basically you put a lot of people, you consider your lobbyist, and then you get them to say the same thing over and over again and if you keep doing that at a break off workshop, people will be like ‘seems like we have reached a consensus about X or reached a consensus about Y’. But really it was a group of people, saying the same thing over and over again”. (A. Dreger, Personal communication, 23. April 2020)

Dreger shared an ISNA archive with the talking points for the meeting. The document consists of two parts: big questions to ask frequently, and gaps in the field that need addressing. The questions were “What are the goal of the treatments and can we articulate that goal?”, “Can we get rid of all terms based on the root hermaphrodite?” and “What can we do to establish a central registry of patients?”. A paragraph followed each question to inform about the reasons for this question and the importance. In the second part, the organisation calls for transitional care for intersex/DSD adults, to get psychosocial care to reduce parental distress and legal protection against discrimination. In the last paragraph, an open question wonders if it would not be useful to speak about the parental experience of children with other forms of birth anomalies. From this document, it is clear that the organisation wanted to have information regarding the current situation for children in hospitals, get away of the idea that intersex is a gender identity and aimed for alliances with the disability movement. Also, nowhere in the document does it stipulate that ISNA wants DSD language but, much more, that medicine should get

---

[2] Original: “Es hätte schon im Vorfeld eine größere Bandbreite von Meinungen eingeholt werden können. So blieb das Gefühl (nicht nur bei den Betroffenen), dass das Treffen in Chicago nur für einen willkürlich ausgewählten, zu kleinen Kreis zugänglich war.”

away from hermaphrodite rooted language; a change from their previous slogan: Hermaphrodites with Attitude.

On their website, ISNA writes that the Consensus statement was a breakthrough on a different level. First, it was a progression towards patient-centred care of intersex children; second surgeries are less automatic and the statement recognises that there is no evidence for parental attachment issues despite parental distress after the birth of their child and lastly, the change in terminology. ISNA wrote that "improving care can now be framed as healthcare quality improvement, something medical professionals understand and find compelling" (Dear ISNA Friends and Supporters, 2008). These changes were in adequation with the development of medicine, shifting away from the paternalistic model. Two years after the Consensus statement, the association defunct. An explanation for that decision is to be found on their website.

> In the current environment, there is a strong need for an organization to assume the role of a convenor of stakeholders across the health care system and DSD communities. It's the primary gap between today's status quo and the wide-spread implementation of the new standard of care we envision. Unfortunately, ISNA is considerably hamstrung in being able to fulfil this role […] there is concern among many healthcare professionals, parents, and mainstream healthcare system funders that ISNA's views are biased or that an association with ISNA will be frowned upon by colleagues and peers. And there is widespread misinformation about ISNA's positions. For ISNA and many of our collaborators, this has been extraordinarily frustrating and has hindered our ability to champion and move forward in this important work. (*Dear ISNA Friends and Supporters,* 2008)

As a result, another organisation was founded, Accord Alliance, which mission is "to promote comprehensive and integrated approaches to care, that enhance the health and well-being of people and families affected by DSD by fostering collaboration among all stakeholders" (*Our Mission*, n.d.).

4.2. Consensus statement and the emergence of transnational activism

4.2.1. Creation of OII network: the beginning of a shift?

When ISNA changed its strategy or militant approach in the early 2000s, to adopt a less confrontational position, frictions and controversies emerged within ISNA but also with individual activists in the USA and internationally. The analysis shows that these frictions not only had to do with a feeling of medicalisation and pathologisation of intersex issues with ISNA's newly preferred terminology, but also with an internationally shared feeling of discouragement. International activists had a feeling that ISNA and consequently, the American voices, were leading the international situation of people with VSC. Cabral (Personal communication, 4. June 2020), remembers being at a Conference in Argentina in 2006, where the new terminology was announced. Cabral (Personal communication, 4. June 2020) feels like the creation of the international OII network, in 2003, had many problems. Nevertheless, an international community was created, which was a transformative movement for the movement. By retracing the history of OII's beginning, the following part will discuss how the international OII network emerged from the two previously mentioned problematics.

From 1993 to the early 2000s, Curtis Hinkle (Personal communication, 18. April 2020), an intersex activist from Louisiana (USA) was an indirect supporter of ISNA's work. While he never was active in the organisation, he claims that he whole-heartedly supported the organisation through financial donations and gave an interview once. In a discussion with Davis (2015), he argues that his support changed in the beginning of the 2000s'; partly because ISNA was shifting away from political mobilisation against medical professionals operating on intersex children, but mainly because ISNA was welcoming medical professionals in the organisation. The inclusion of medical voices in the organisation and board negatively influenced the direction of the association's advocacy. For many of the early activists, who were not part of ISNA, the strategic change was a result of medical corruption. Betsy Driver (Personal communication, 26. April 2020) says that doctors were using or gas lightening ISNA's advocates, who did not realise this until it was too late. Hinkle maintains (Personal communication, 18. April 2020) that ISNA was won over by doctors and health practitioners because the activists were invited on trips and nice dinners. Furthermore, he claims that he would never have accepted all the attention from doctors, as he wanted to oppose them; "You do not sleep with the enemy" (C. Hinkle, Personal communication, 18. April 2020). The current analysis does not look at the veracity of these accusations, but perceives the climate of anger and disappointment as parts of the driving forces for the creation of the international network. When Hinkle (Personal communication, 18. April 2020) found out that ISNA was changing the terminology to DSD; he was angry as in his eyes, this represented a set back of the movement by decades. Hinkle was not the only person against the change in terminology and the utilisation of DSD instead of intersex. Morgan Carpenter (Personal communication, 23. April 2020) remembers taking part in discussions on the forum Body Like Ours. For him, ISNA and their allies should have realised that this was going to be problematic and result in further pathologisation of intersex variations. Betsy Driver (Personal communication, 26. April 2020) explains that the political objective of the forum was indirect. Its objective was to strengthen the voices of intersex people and to show the number of testimonials claiming that intersex surgeries are dangerous. A feeling of helplessness was occurring, Hinkle (Personal communication, 18. April 2020) explains that ISNA's approach was perceived as paternalising towards other intersex people. Despite multiple opposition from intersex individuals who strongly refuted the DSD language, ISNA kept its mindset. He claims that the leading voices of ISNA were "treating the community as a bunch of babies" (C. Hinkle, Personal communication, 18. April 2020), leading him to create his organisation. As a linguistic graduate, Hinkle was attentionate to language and argued that DSD was going to increase the institutionalisation of VSC. He says:

> People [ISNA] would not listen to me about how important words are. Words are extremely important. Words are used to police people. To attack people. To keep people in line. To put people in their place. Words are powerful. So, if you are starting out with 'disorder of sex development', what do you expect for a consensus statement 'It's all going to be treat, treat, treat, treat'. If it's a disorder, we have to put an order into place. We need some order here. (C. Hinkle, Personal communication, 18. April 2020)

In this statement, Hinkle touches on two different theoretical components that were mentioned in the theoretical part: medicalisation and pathologisation as well as medical power. First, as Conrad and Schneider (1992) argued, the word disorder is part of the institutionalisation of some deviant characteristics in medical establishments. Medicalisation is not fundamentally a negative experience for all, as some social movements are advocating for a medicalisation of their realities to access the care they need. However, both ISNA and Hinkle were advocating against the pathologisation of VSC. There seems to be a commonality amongst intersex activists;

medicalisation is necessary to access healthcare as consensual treatments should be paid by the health care system, which would not be the case if VSC were not medicalised. Also, as Mauro Cabral (Personal communication, 4. June 2020) explained, medicalisation and pathologisation of VSC take place on different levels. On one side, it takes into account whether the body has a health concern (such as salt-wasting) or if it is just part of natural bodily diversity (such as having or not a vagina). Then, on the other side, medicalisation and pathologisation of intersex bodies should also consider whether the body is in an unhealthy state because of medical interventions. Karkazis (2008), amongst other scholars, claimed that the medical power lays in its authority to decide whether a deviance is natural and healthy or not. This connects to the second theoretical aspect, which is medical power. Indeed, this refers to Foucault's three types of power relationships: sovereign-power, disciplinary-power and bio-power (Lilja, Vinthagen, 2014). With the institutionalisation of DSD nomenclature, it is arguable that this gave medicine aspects of all three power types, and especially disciplinary-power and bio-power. The Chicago conference gave doctors the responsibility to create knowledge on intersex, receiving the authority to make claims, investigations and to understand VSC. With the Consensus statement, language, perceptions and a code of conduct were decided, fostered within the medical discipline. When looking at bio-power, the DSD terminology gives to medical institutions the power to regulate the sexual functions of the body. While the Consensus statement does believe that "homosexual orientation (relative to the sex of rearing) or strong cross-sex interest in an individual with DSD is not an indication of incorrect gender assignment" (Hugh et al., 2006, p. 556), the objective of hormonal treatments and surgical interventions are still to enable the child to fit the heteronormative, binary norms of sex, gender and sexuality. Hence, reductions of clitorises are still recommended if the clitoris is considered severely virilised.

In a post on OII's website, a list of reasons why the organisation rejects DSD terminology is to be found (Curtis, 2007):

A. Reducing intersex to a genetic defect
B. American imperialism and the abuse of power to define others
C. Increased pathologisation of the intersexed child throughout their childhood and adolescence
D. Exclusion of intersexed people
E. Pathologising only the gender atypicality of intersex bodies with little emphasis on the underlying specifics of the particular intersex variation

F. Eugenics research
G. Entrenches arbitrary gender assignments without consultation with the child
H. Sexism
I. Transphobia and homophobia
J. Even in English speaking countries, this term will make it more difficult to speak to the actual child about being intersex.

The list shows how problematic the new terminology was for OII members and the feeling that medical power was reasserted. The belief that DSD is increasing the authority of medical establishment over intersex/VSC bodies has also been claimed in many different activists' press releases, blog posts and articles from the time, for example:

> If intersex is a disorder, that means that it is a disorder that someone has; the problem has to do with the individual, and the way the problem has been fixed is to fix the individual (preferably before it becomes a problem for society). (O'Brian, 2009)

In addition to a strong opposition with the DSD terminology and predictions that this will be hurtful for the movement, many intersex activists explain that they were tired of the American model of intersex activism. While, as mentioned earlier in this paper, ISNA was not the only national intersex group at the time, it failed to frame its message that way. On the contrary, AGGPG already spoke about human rights, genital mutilations and the desire for legislative actions. ISNA defined itself as a patient organisation and framed its concerns as a question of health. Only when the USA was banning female genital mutilations, did ISNA frame its demands as a human rights issue (Ehrenreich & Barr, 2005; Chase, 2002). In that context of extreme opposition to the new nomenclature, ISNA's change of strategy and the medicalisation of the association, Hinkle (Personal communication, 18. April 2020) decided to create an international organisation. As a multilingual speaker, he decided to write to people in different parts of the world in their language. Following this strategy, OII kept increasing internationally, staring with languages-based chapters like OII Francophonie or OII Chinese and then adding country-based chapters like IHRA, OII Germany or OII USA. As Dan Christian Ghattas (Personal communication, 29. April 2020), who is the executive director of OII Europe explains, this development from a global to a national/regional movement, "makes the movement very different from all other movements [he] knows of" (D. C. Ghattas, Personal communication, 29. April 2020). At the beginning, OII was mainly individual activists in different regions of the world, and the international network gave activists a sense of belonging. Ins A. Kromminga, an intersex artist who is one of the founders of OII Germany, explains that "the network was an email list and it included people from all over the world" (I. A. Kromminga, personal communication, 21. May 2020). This was good as at the time activists were often alone. It gave them the possibility to connect over the internet and reduce the feeling of loneliness. Kris Günter (personal communication, 2. April 2020), nevertheless explains that during the beginning years of his activism, he was quite lonely as all contacts were done via email and that he was missing personal contacts.

On top of the conversation that led the consensus group to adopt the DSD nomenclature, Mauro Cabral believes that "the intersex community was kind of fed up with the US" (M. Cabral, Personal communication, 4. June 2020) and that at some point it was the USA (in other words ISNA) against the rest of the word. This statement seems to be congruent with other activists' claims. Hinkle (Personal communication, 18. April 2020) explains that he got fed up by the advocacy approach in the USA that he felt was paternalistic. Besides his strong language skills, one of the reasons why OII became an international network was so international voices could be strengthened and because it was complicated to create another organisation in the US. He states that ISNA and the US community were attacking him, forcing him to found OII in Quebec to get his message out in a language other than English.

The previous parts on ISNA showed that the association was an HSM, as described by Williamson (2008). While OII also tries to change the medical establishment, the strategy and approach are very different. OII and the international intersex community have a more radical approach (like ISNA in its first stage), uses identification principles such as choice, respect but also equality, which is quite unusual for HSM. More than collaboration with medical professionals, OII and the international intersex community forming in resistance to ISNA's new strategy makes it seem that it is a social movement trying to change a social instead of a medical order.

4.2.2. Creation of a global intersex agenda: the role of ILGA

Since the 1990s intersex organisations and activists have been working with LGBT communities and especially the trans community. As mentioned before, ISNA was firstly working with LGBT organisations before trying to distance itself of the politicisation the collaboration resulted in. While, in hindsight, acknowledging that working with the LGBT communities has brought some positive changes to the movement, Alice Dreger (Personal communication, 23. April 2020) explains that being LGBT is an adult self-identity much more than a paediatric one. The politicisation of intersex made the collaboration with doctors increasingly difficult and hindered the association's goal. Other organisations, such as AGGPG in Germany, have drawn similarities with the trans community (Reiter, 1999). The analysis shows that ILGA World and especially its sub-organisation ILGA-Europe have played a central role in the professionalisation of the global IHRM. The following part will look at how intersex has been taken up by ILGA during the ILGA World conference in 2008 in Vienna (*Vienna 2008*, n.d.) and more specifically, what that meant for ILGA-Europe. It will also identify the role and effects of the three first international intersex forums (IIF) in the emergence of a global IHRM.

Before starting the analysis, it is essential to contextualise ILGA and ILGA-Europe's mission and advocacy. ILGA World was constituted in 1978 as the International Lesbian and Gay Association but was renamed in 2008 as the International Lesbian, Gay, Bisexual, Trans and Intersex Association, when it included intersex and trans issues in its mandate. Its vision, as the website states, is:

> A world where the human rights of all are respected - regardless of a person's sexual orientation, gender identity, gender expression and sex characteristics. A world where everyone can live in equality and freedom, where social justice is ensured and the diversity of LGBTI people and their communities is valued. (*Annual Reports and Documents,* n.d.)

Members of ILGA World are non-profit organisations, non-profit groups and organisations of public law (Constitution of ILGA, 2019). It is a network constituted of regional organisations: Pan Africa-ILGA, ILGA-Asia, ILGA-Europe, ILGA-LAC, ILGA-North America, ILGA-Oceania (ILGA World Member Organisations, n.d.). Since 1996, ILGA-Europe has been an independent entity from ILGA World, advocating for human rights and equality at a European level, engaging in strategic litigation and aiming to strengthen the movement. The latter is fulfilled by facilitating trainings, building capacities and supporting "its member organisations and other LGBTI groups on advocacy, fundraising, organisational development and strategic communications" (What is ILGA-Europe, n.d.).

When ILGA World included intersex issues in its mandate and changed the name of the organisation, Silvan Agius (Personal communication, 30. May 2020) was the policy director at ILGA-Europe. As he was working on trans issues, it made sense for ILGA-Europe that he was also going to be in charge for intersex issues. While sex characteristics and gender identity are not inherently connected, there seems to be an assumption that both go together. Some organisations, and activists, feel like this combination is hurtful to the intersex movement, as it shifts the focus away from bodily autonomy and medical harmful practices. Until 2011, Agius explains that the work ILGA-Europe was doing was mainly research and connection to understand the problem, talk with the community and see how ILGA-Europe could push the movement forward. As ILGA-Europe was receiving substantial funding from the European Commission and other donors, there was much pressure to engage in that field actively. The name change, therefore, represented much work for ILGA-Europe, and Silvan Agius, who needed to understand the issue, find the community and start advocating. The first years of his work on intersex were challenging as he did not have sufficient knowledge and understanding on that matter. Before Agius did anything, his role was to find the intersex movement. In his search, he got in touch with the Belgium organisation Genres Pluriels, which Kris Günter had just joined (K. Günter, Personal communication, 30. June 2020). Agius (Personal communication, 30. May 2020) contacted Genres Pluriels for two main reasons: it was in Brussels where ILGA-Europe's office is and had a queerer identity than most organisations he knew at the time. The organisation included intersex people and issues. While he hoped to meet the intersex community from Belgium, he found out that Kris Günter was the only intersex person in the organisation. Genres Pluriels then redirected Agius to an organisation in Berlin, TransInterQueer (TrIQ), in which Dan Ghattas and Ins A. Kromminga were part of. Like at Genres Pluriels, the intersex nucleus of TrIQ was very small which made Agius wonder how to start his work on intersex issues. In 2009, Ghattas (Personal communication, 29. April 2020) was invited by ILGA-Europe, on the initiative of Transgender Europe (TGEU), to the trans pre-conference. ILGA-Europe organises an annual conference over a couple of days; the pre-conference finds place a day before the actual conference and addresses groups under the LGBTI acronym individually. Thus, the trans pre-conference in 2009 was a day consisting of workshops and meetings designed explicitly for the trans community. During the pe-conference Ghattas informed participants on intersex issues and got in touch with people that would become important for the nascent intersex activism on a European level. In 2010, after a year of collaboration with Silvan Agius, Dan Ghattas (Personal Communication, 29. April 2020) says that he pointed to the desperate need of the international intersex community to meet, and suggested an intersex pre-conference. Until then the community only wrote to each other through the internet and the OII email list. The conversation was taken further and developed into the idea of having an international intersex forum (IIF) independently from the ILGA-Europe Annual

Conference. In consultation with Genres Pluriels and IHRA, the organisation of the IIF started. From 2011 to 2013 forums were organised yearly; in Belgium, Sweden and Malta, respectively. These were for many of the participants the first time activists physically saw each other. Until the IIF, the intersex movement mainly consisted of one to two activists in a country, who connected through online chat groups. Ins A. Kromminga (Personal communication, 21. May 2020) explains that taking part in the first IIF meeting was overwhelming as they could meet all their heroes, meaning activists from all regions of the world they looked up to. Kris Günter (Personal communication, 21. April 2020) also found the forums very positive as he could meet the community, learn from experiences around the world and make new friends. He also claims that OII Belgium was funded after the first forum as an actual organisation. In 2006, there already was an OII Belgium blog but not a militant organisation per se.

> ILGA-Europe is a learning organisation and it has now become a tradition for the board and staff to host a joint training session each year. This year the training was dedicated to the rights and issues of intersex people. This was a direct result of our new Strategic Plan according to which ILGA-Europe needs to build its capacity on intersex issues before we can speak and act with legitimacy and confidence about this complex issue. (ILGA-Europe, 2011)

Before the first IIF, Dan Christian Ghattas and Mauro Cabral facilitated a workshop on intersex issues for the board and staff of ILGA-Europe and ILGA World (D. Ghattas, Personal communication, 29 April 2020, M. Cabral, Personal communication, 4. June 2020, S. Agius, Personal communication, 30. May 2020, ILGA-Europe, 2011). This one-day training included "ways of talking about intersex issues, a historical perspective of how intersex issues developed over time, mapping of intersex organisations and reaching out to them, and ways for ILGA-Europe to include intersex issues in its advocacy" (ILGA-Europe, 2011). Like the citation of ILGA-Europe's Annual Report shows, this training gave the participants the knowledge to engage in intersex activism and support advocates with legitimacy. Silvan Agius (personal communication, 30. May 2020) confirms this by claiming that by undertaking this one-day training ILGA World and ILGA-Europe could grasp the baseline of intersex activism.

When organising the IFF, Agius (personal communication, 30. May 2020) faced different challenges. Firstly, he had a budget for a limited amount of people who needed to come from as many countries as possible. "This is how a European movement is created", he confirms. Furthermore, there were discussions about the selection process of the participants, as these forums were not supposed to be medical or patient-group meetings. Lastly, he had to ensure that the meetings provided a safe space for everyone to express themselves freely. Even if some controversies persisted during and after the forums, it is safe to claim that the IIF catalysed the emergence of an intersex movement. The organisation, goal and outcome of each forum will be outlined hereafter. The issue of the institutionalisation of intersex issues in the LGBT mandate will also briefly be mentioned.

First international intersex forum, Brussels: 3rd to 5th September 2011

The first IIF aimed to create a network of intersex activists, share best-practices and approaches to advocacy in each region as well as foster international collaborations amongst intersex activists. Furthermore, it had the objective to get to an agreement regarding the needs of intersex people. Lastly, it was supposed to situate the work that transnational LGBTI umbrella organisations, such as ILGA, ILGA-Europe, TGEU and International Lesbian, Gay, Bisexual, Transgender, Queer & Intersex Youth and Student Organisation (IGLYO), could do on intersex issues. The two first days aimed to come up with an agreed manifesto by holding group discussions, reflections and action planning. The last day had the objective to enable the advocates to exchange ideas with the international organisations to find ways to engage with regional and international human rights mechanisms (Equality Works, 2011). With the aim, goals and approach of the forum, it is clear that ILGA-Europe was trying to build a European and international community that would engage in transnational activism and utilise the international human rights law system to achieve its means. During that first forum, Agius (Personal conversation, 30 May 2020) claims that many points had to be discussed; the pain and mistrust, the damage of the intervention on the body and psyche as well as the willingness to create a social movement. The interviewees who participated in the forum claimed that this first meeting was empowering on a personal and political level.

The drafting of the three demands (Annex A) that composed the ending statement of the forum materialised a feeling of collective power, collective strength and a new advocacy strategy. Ins A. Kromminga (Personal communication, 21. May 2020) remembers thinking when this first statement was drafted and published that this was the beginning of something huge.

> I think there is power in connecting people at an international level. I think that was the first time I realised that there is something we can use for our work, this makes an impact that we, as a small individual activist in our little organisation

> are able to move that much. (I. A. Kromminga, Personal communication, 21. May 2020)

Second international intersex forum, Stockholm: 9th to 11th December 2012

The second forum built upon the work of the first one. It came up with agreements on priorities for the intersex movement, strategies and understandings of critical characteristics of the intersex movement (*2nd International Intersex Forum*, 2012). Agius (Personal communication, 30. May 2020) explains that there already was a change in this second forum as people were familiar with each other and had expectations. Also, more participants were invited to the second forum: 24 activists representing 17 intersex organisations in 2011 and 37 activists representing 33 intersex organisations in 2012 (*2nd International Intersex Forum*, 2012; *First ever international intersex forum*, 2011). Amongst the new participants were the representatives of StopIGM.org, who currently have a more critical vision of the ILGA and ILGA-Europe's work on intersex and the utility of the forums. At the time, however, Daniela Truffer (Personal conversation, 8. May 2020) remembers thinking it was great to be invited and to meet other intersex people.

The outcome of the second forum was an addition of four demands to the three developed in Brussels and four calls towards human rights institutions (see annexe B). The activists addressed its claims towards the UN as well as regional and national human rights institutions, which shows the direction the movement was taking. Especially the first call demanded "the United Nations to take on board intersex rights in its human rights work" (*2nd International Intersex Forum*, 2012) and was accompanied by an open letter to the then UN Human Rights Commissioner, Navanethem Pillay (*Open letter: A Call for the Inclusion of Human Rights for Intersex People*, 2012).

> We are writing to discuss the grave situation of human rights abuses of intersex people worldwide. We are concerned about the specific uses of prenatal Dexamethasone (DEX), nonconsensual medically unnecessary surgeries on infants and minors, the gross mistreatment of Pinki Pramanik, and the recent addition of intersex people under the language of "DSD" (Disorders of Sex Development) to the DSM-V. (*Open letter: A Call for the Inclusion of Human Rights for Intersex People*, 2012)

With this letter, it resonates that the common ground amongst the global IHRM is an opposition to the pathologisation and treatment of people with a VSC. The fact that the participants address international, regional and national human rights institutions also illustrates the articulation of the movement that is forming, and that is taking a human rights approach using the international human rights law systems.

Third international intersex forum, Valetta: 30th November to 2nd December 2013

The third IIF was different from the two first ones. Agius (Personal communication, 30. May 2020) claims that the difference was firstly found in the dynamic of the event; people knew each other and were confident that there was an intersex movement. Secondly, the Maltese minister, Helena Dalli, came, as well as the European Human Rights Commissioner, Nils Muižnieks, and representatives from Amnesty international. From the discussions at the third IIF, the Malta Declaration came out. The Malta Declaration was "the anti-2006 consensus statement. The document that tears the other one down. That is *our* document, and the Consensus statement is *theirs*" (S. Agius, Personal communication, 30. May 2020). Morgan Carpenter (Personal communication, 23. April 2020) has the same perception of the Malta Declaration than Agius, he also believes that it was the beginning of something new for the intersex movement. He claims the period between the Consensus statement and the Malta declaration was a time of significant turmoil. Some organisations were trying to be patient's rights organisations and accommodating their language to the medical one. On the contrary, other organisations wanted to form a human rights movement. For Carpenter, however, it was only with the Malta declaration that a consensus was created amongst intersex organisations.

Seemingly, the creation of a global intersex agenda has been highly influenced by ILGA and ILGA-Europe's financial and experiential support. However, most participants came from predominantly industrialised countries. Mauro Cabral (Personal conversation, 4. June 2020) says that there were "four forums happening in Europe with a majority of representative from Europe and the US, for the movement in global South it has been a very painful experience". Fact is, many countries from non-industrial countries have written statements after 2015, which could potentially show that they did not feel included in the movement or that they have specificities that, due to lack of representation, were not taken into account sufficiently. For instance in 2017, the African intersex movement published a public statement, which firstly demands "To put an end to infanticide and killings of intersex people led by traditional and religious beliefs" (*Public Statement by the African Intersex Movement*, 2017) or in

2020 Russia released the Moscow Statement (*The Moscow Statement (Statement of The Russian Intersex Community*), 2020), illustrating the existence of discrepencies. While this paper mentions the global IHRM, it is important to acknowledge that this is a generalisation, and that, like too often, the voices of the persons coming from the Global South, newly industrialised countries or developing countries are not given enough credit.

Building upon the theory on living rights, social justice and translation, it seems both, the exploratory stage and the organisation of the IIF recontextualised intersex rights outside of a patient's rights movement to a human and children's rights perspective. As mentioned previously, rights evolve through interaction, discussion and the unpacking of new social issues (Merry et al., 2010). Already before the adoption of intersex in the ILGA mandate, intersex groups were organising themselves virtually or physically to shape and define their cause. Nevertheless, through the scope and means that ILGA and ILGA-Europe had, this sharing-process could be catalysed and made more efficient. Intersex rights were already defined in a way by ISNA using the human rights values that Merry et al. (2010) mentions as human dignity, equality, non-discrimination, bodily integrity and freedom. While they had a particular set of values that were specific to human rights, the organisation failed to use human rights as a system of law and as a vision of good governance. The forums were bringing people from all continents together and permitted the creation of a collective narrative with shared values. The forums were also giving advice and tools to national groups and individual activists on how to use international and regional mechanisms as a system of law. While Merry et al. (2010) explain that these mechanisms are surprisingly open to dialogue with and include seemingly powerless groups, they can be overwhelming and seem difficult to use. During the first two IIF, trainings and sharing sessions were organised, and in Valetta, human rights representatives were there. Hilda Vilora (2017), for instance, wrote in their book about their experience at the second IIF and how ILGA and ILGA-Europe helped them to write their open letter to the Human Rights Commissioner at the UN to make it stronger. This is one example from a bigger picture as explains other interviewees explained.

> We are essentially trying to create a new set of normative frameworks that can be effective in addressing the issues opposed. For me, I think, one of the key issues is that medicine is one of the most powerful institution that exists and many other… almost every other institution will differ to it […]. So, I think we needed strong allies and normative frameworks that can articulate the issues

> that we care about in a meaningful way. That can be understood by people. And I think human rights frameworks are those frameworks. We had to learn what the Convention of the Rights of the Child had to say, that's important… We have to learn about the CRPD and how the UN system works. And I think there are some people that were leading in that. (M. Carpenter, Personal communication, 23. April 2020)

That relatively lengthy statement from Morgan Carpenter illustrates that the IIF and the conversations that came out of them created the new normative framework, the values and gave the IHRM tools to engage with the international and regional system. It enabled the movement to use the human rights systems as a system of law, a set of values and a vision of good governance (Merry et al., 2010). Mauro Cabral (personal conversation, 4. June 2020) was already working with the human rights system before the Consensus statement, as he recalls. In 2005 he was working for the International Gay and Lesbian Human Rights Commission (which is now called OutRight Action International) and spoke at the UN in different international human rights settings on intersex issues. Nonetheless, Cabral was for a long time the only intersex person in the room, and believes that the forums were a place where intersex people could start organising and creating their activism. StopIGM's representative Daniela Truffer (Personal communication, 8. May 2020), tried to engage with international human rights institutions before the IIF as well. As a representative of Intersexuelle Menschen e.V. at the time, she participated in the writing of the first shadow report to CEDAW in 2008, but did not get satisfying recommendations from it. This might be from a lack of experience or awareness in the UN of intersex issues. Ins A. Kromminga (Personal communication, 21. May 2020) explains that for them, going international, in the sense of using the international and regional human rights law systems, was a way to confront doctors at the same level they organise. As the doctors were organising internationally, it was only reasonable for the IHRM also to go international. That is what they call a grassroots top-down approach. While the organisation of the IIF has been discussed previously, this statement is illustrative of the desire of the movement to fight against doctors at the same level of organisation as medical professionals.

While adding intersex to ILGA's mandate has catalysed and professionalised the IHRM, Daniela Truffer and Markus Bauer from StopIGM.org (Personal communication, 8. May 2020) are doubtful about whether it is positive for intersex issues to be part of the LGBT mandate. From their experience, the intersex movement has lost some of its revolutionary approach by joining the rainbow community. They regret that the IHRM is too centred on gender identity instead of bodily integrity and opposing doctors and medical professionals. For them, as LGBTI and feminist foundations often fund the IHRM, the movement has to follow certain principles that are not connected or sometimes even hurtful to the movement. They fear that being connected to the LGBT community is frightening doctors and parents, who do not want their child to be part of it. Mauro Cabral (Personal communication, 4. June 2020) believes that it is not the right way forward for intersex to be linked to gender identity. Much more, he aims to frame intersex as a concern of bodily diversity. He thinks that it is right for the intersex movement to be part of the LGBTI community, but that part of the problem with the LGBT movement is that intersex people do not have a position of power, making the relationship to the LGBT movement asymmetrical.

4.2.3. Human rights statements: symmetrisation of power relations?

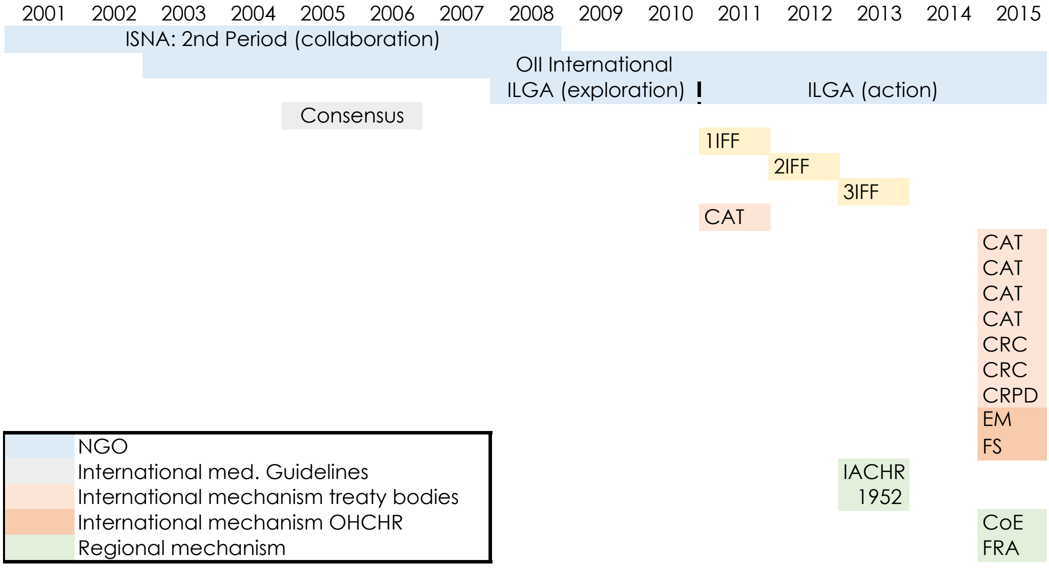

Figure 2: Institutionalisation of intersex issues in human rights mechanism. (Personal illustration)

The previous chapter examined how the three first IIF enabled the establishment of common ground claims between intersex activists from all continents. Furthermore, it argued that intersex rights are living rights and that through a process of translation, social movements such as the IHRM, can reach social justice. While the translation process of ISNA was focused on a collaboration with medical professionals and the creation of medical guidelines that would speak against surgical or hormonal treatments on children with a VSC, the forming IHRM used the international human rights law system to achieve its mean. As depicted in figure 2, since 2011, many strong recommendations and reprimands from various treaty bodies have been published. The Swiss organisation StopIGM.org, which mainly works with international human rights law systems, explains that:

> There needs to be a prohibition and there needs to be consequences for doctors who do it [mutilations]. And unless there are sanctions and accountability, nothing will change except on the surface. And that's why we always say that we want a prohibition in the criminal law, and the crucial point is, I think, the status of limitation, because with normal status of limitation for bodily assault, the status of limitation have expired before the person concerned is an adult and capable of suing the doctor. (Personal communication, StopIGM.org, 8. May. 2020)

Since 2011, there have been two significant evolutions in the UN. The first consists of the repeated submission of lists of issues and shadow reports in different treaty bodies, while the second includes an Expert meeting that occurred on the 16th of September 2015 on ending human rights violations against intersex persons. In 2011 and 2015, the CRC, CAT and CRPD have released a total of eight specific concluding observations going in the direction of intersex human rights. The CAT for Switzerland, for example, writes that the state:

> Should take the necessary legislative, administrative and other measures to guarantee respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child. (*Concluding observations on the seventh periodic report of Switzerland*, 2015)

Furthermore, the CAT demands that investigations on the surgical treatments that have been done to children in Switzerland are undertaken to "provide redress to the victims of such treatment, including adequate compensation" (*Concluding observations on the seventh periodic report of Switzerland*, 2015). The same year, the CRC refers to these treatments as harmful practices and considers them as genital mutilation.

> While welcoming the adoption of a new provision of criminal law prohibiting genital mutilation, the Committee is deeply concerned at: […] (b) Cases of medically unnecessary surgical and other procedures on intersex children, without their informed consent, which often entail irreversible consequences and can cause severe physical and psychological suffering, and the lack of redress and compensation in such cases. (*Concluding observations on the combined second to fourth periodic reports of Switzerland*, 2015)

In Germany, the CRPD is concerned by the situation of bodily integrity of intersex children. It calls on the country to implement the recommendations of the CAT that were published in 2011 (*Concluding observations on the initial report of Germany*, 2011). Similar concluding observations by these treaty bodies have been released for state parties such as Hong Kong, Australia or Chile.

StopIGM.org representatives (Personal Communication, 8. May 2020) point out that the publication of the Consensus statement has simplified their advocacy at the UN. The document has been criticised vigorously by intersex advocates, but Daniela Truffer claims that this is an excellent tool to attack doctors as it does not condemn intersex surgeries and represents the recent medical standpoint. The increasing concern and institutionalisation of intersex issues regarding bodily integrity as well as the work of the IHRM have made the Office of the High Commissioner of Human Rights (OHCHR) aware of intersex issues. The OHCHR participated in the organisation of the first Expert meeting, which aimed, as said by the Commissioner for Human Rights at the time, Zeid Ra'ad Al Hussein, to end human rights violations. Zeid Ra'ad Al Hussein admits not having had much awareness on intersex issues until 2014, when he started his mandate. For him, the presupposition that everyone can be categoriesed in a biological dichotomy is one of the core reasons for the severe human rights violations that intersex people face: medically unnecessary surgeries, invasive treatments on infants and children, infanticides and life-long discrimination. As these violations are not often discussed and rarely investigated, perpetrators feel impunity and a vicious circle of ignorance and abuse is perpetuated (*Opening remarks by Zeid Ra'ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert meeting on ending human rights violations against intersex persons*, 2015). Dan Christian Ghattas, Daniela Truffer, Mauro Cabral and Morgan Carpenter were some of the intersex members a part of the civil society activists who were invited to this Expert meeting. Morgan Carpenter (Personal communication, 23. April) remembers that it was a two to three years process of discussion with the OHCHR, which resulted in the Expert meeting and a fact sheet on intersex issues for the Free and Equal campaign. For him, the movement increased skills working with global human rights bodies.

At a regional level, the European Fundamental Human Rights Agency published a paper in 2015 on the situation of intersex people in Europe, concluding that operations should be avoided. The same year, the Council of Europe published an issue paper, prepared by Silvan Agius, on intersex people and human rights. The first recommendation out of the eight demands to member states was to end medically unnecessary treatment on intersex persons, which include irreversible genital surgery and sterilisation. (Council of Europe, 2015). Kris Günter (Personal communication, 21.

April 2020), who was on the board of OII Europe, explains that the collaboration with the European Commissioner of Human Rights has been excellent and that the Commissioner was very invested in the topic. This type of investment was not Günter's experience with all people he had the opportunity to work with during his time on the board. However, a year after the publication, eight doctors, some of whom were involved in the Consensus statement consortium, published an article in European Urology entitled *Response to the Council of Europe Human Rights Commissioner's issue paper on human rights and intersex people* in which they claim that the issue paper has four main problems (Cools, Simmonds, Elfold, Gorter, Ahmed, D'alberton…, 2016):

1. LGBT movement representing the people with a DSD,
2. The views of intersex activists are not representative of the affected community,
3. The issue paper does not recognise the evolution that happened in the field of medicine, and
4. The term intersex is inappropriate for a majority of medical professionals, parents and patients.

Dan Ghattas (Personal communication, 29. April 2020) remembers being to a certain extent surprised by the impunity and arrogance of the medical professionals showing in the public claim that the European Human Rights Commissioner had basically "not done his homework". Agius (Personal communication, 30. May 2020) does not remember this article but claims that doctors speaking up against the issue paper is an indication that their practice continues. Undeniably, intersex bodily autonomy is increasingly perceived as a human rights issue; international and regional human rights mechanisms have been critical tools for the movement to frame unconsented and unnecessary treatments as mutilation and harmful practices. Nevertheless, two plays for power have been identified between the IHRM and medical institutions. The first concerns the chosen language and the second regards the quantity and quality of the political oppositions.

The concern regarding wording is history repeating itself in a certain way. The term intersex is continuously being politicised and not only as a queer or feminist term but also, even if this is not exclusive from one another, as part of human rights language. On the contrary, DSD continues to be used in medical settings, whether it is in literature or when disclosing a diagnosis.

> Everyone says "intersex this" and "intersex that", stop intersex surgeries, buzz word, all of this…. Everyone says that. In term of activists, they go into the media,

> they publish, they do research on intersex and meanwhile, in the hospitals and care centres, doctors are not telling the parents that their child is intersex. They are telling them they have a disorder of sex development or diagnosis specific language. Which then I wonder, if they are continuing to escape that criticism… It is actually kind of brilliant. (G. Davis, Personal communication, 20. April 2020).

In an Australian government known as the Australian Capital Territory (ACT), a third sex category was created in 2014 for intersex children. The objective was to "reduce the risk that parents will force their child to conform to a particular gender or subject them to gender assignment surgery or other medical procedure to match the child's physical characteristics to the chosen sex" (Letter by K. Gallagher, cited by Carpenter, 2018). However, as of 2020, no child has ever been assigned to this third category. While this might imply that no child was born intersex, a statistically unlikely possibility, in another letter that Carpenter (2018) received from the Chief and Health Minister of the ACT, K. Gallagher, mentions that children born with a DSD undergo treatments in line with the Consensus statement. As Carpenter notes "Those two letters from the Chief and Health Jurisdiction in Australia show how the discourse on intersex and the discourse on DSD could be talking about two different populations" (M. Carpenter, Personal communication, 23. April 2020). Therefore, with both the language of intersex and DSD existing, medical institutions can frame their message differently, as if both words were addressing different populations. In that sense, doctors escape the criticism coming from the human rights institutions and speak about DSD as a medical or abnormal condition and intersex as a gender identity concern. Mauro Cabral (Personal conversation, 4. June 2020) argues that this is why the intersex movement is building alliances with movements that aim to get representation in bioethical committees, dismantle the power relationships in a medical setting, and address the human rights violations in hospitals and clinics.

The second authority comes from the quantity and quality of statements as well as the numerous tentative to change national policies and laws. While national governments officially have the authority to regulate medical practices, healthcare professionals are effectively given the authority to determine medical governance. The state of protection around intersex/VSC internationally illuminates this, as only Malta has banned surgeries in the Gender Identity, Gender Expression and Sex Characteristics Act in 2015, as a direct result from the third IIF in Valetta in 2013 (Garland & Travis, 2020). Similar legislations have tried to pass in different countries but remained, for the moment, unsuccessful.

> I do think that by putting pressure on to state legislations and by putting pressure on to the medical societies and communities, they are realising that you are not just sitting in a corner giving up a fight […] you are organizing the boxing matches they are forced to participate in. And you may not win but at least you make them go on the defence. They do not know when the next bill is going to be introduced and when they do know, they are going to have to put up resources… and it does raise public awareness, it does raise issues and it makes them start to think twice about it. (G. Davis, Personal communication, 20. April 2020)

Seemingly, engaging with both, international human rights law and the national systems, puts pressure on medicine, opens up conversations and raises awareness. Human rights activism is therefore a vector for change, even if its impact is indirect. Mauro Cabral (Personal communication, 4. June 2020) argues that despite the growing number of documents, the medical practice stays unchanged. Either way, when he meets doctors to discuss the situation of intersex people, he frames his speech as if he was on their side. He states that these unconsented and unnecessary medical interventions are soon going to be illegal and that he does not want to see these doctors go to jail. This view is similarly held by Agius (Personal communication, 30. May 2020), who claims that bashing doctor is not helpful to the intersex movement and not the right way forward to push reforms through. The voices of allied doctors are important and bring credibility and value to political demands. As governments are reluctant to intervene in medical practice, if doctors argue for the necessity of interventions, it is going to be challenging to push a law through. In that context, collaborations with allied doctors can make the movement stronger. However, this points towards epistemic injustice as medical voices still have more legitimacy or credibility to address human rights concerns they, as an institution, are perpetrating. Dan Christian Ghattas (Personal communication, 29 April 2020) is disappointed about the slowly raising number of doctors with a human rights perspective.

In conclusion, since 2011, through the creation of a collective narrative during the IIF, intersex issues have been institutionalised in human rights frameworks. In addition, the first national regulations have been drafted to stop unconsented and non-necessary treatments on children with a VSC. However, two problems persist, namely the terminology differential between human rights and medical language and the reluctance of national governments to intervene with medicine.

Chapter 5. Discussion: the vicious circle of medical authority

One of the most difficult battles for the intersex movement is to make medicine change its practice. While raising awareness and being visible is also important for the intersex movement, its primary goal is to protect the bodily integrity of children. As this paper has shown, in the past 30 years the movement has evolved and the ways in which it brings intersex rights to life have changed drastically. At first, there were protests in front of medical institutions that aimed to bring visibility to the cause, shaming doctors who have engaged in such practices because "they must feel the pain too" (StopIGM.org, Personal communication, 8. May 2020). Then, there was a time of dialogue and collaboration. During that period, the movement aimed to change the hearts and minds of doctors and believed that it is more efficient to talk to them, instead of going to court or changing the law. Alice Dreger (personal communication, 23. April 2020) remembers that the organisation "wanted to change the way they [doctors] thought about this. Not just the way they practice […]". However, she thinks in the aftermath that ISNA and herself underestimated "how stupid the medical professionals are". After deceptions and controversies about this second type of organising, the movement began to engage with international human rights law systems and demanded a ban of non-consensual and non-vital treatments on intersex children in the criminal law. While the strategies have been varied, the actual changes in medicine are low, as Ulrike Köppel's (2016) study in Germany has shown. After conducting interviews and analysing medical papers and human rights articles, a specific vicious circle came up, as illustrated in figure 3.

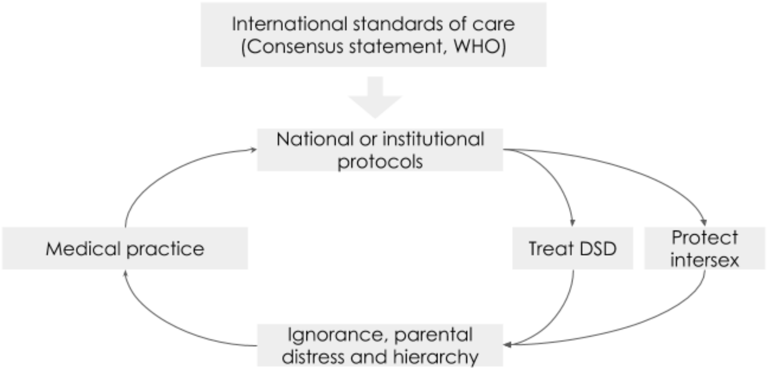

Figure 3: The vicious circle of medical authority. (Personal illustration)

This circle begins with international medical influences. Starting in the 1950s with the John Hopkins paradigm, this process evolved to the Consensus statement and encompasses the WHO. However, their influences greatly vary. While the international standards of care give recommendations regarding the management of patients with a VSC, the WHO and the ICD create frameworks. Mauro Cabral (Personal communication, 4. June 2020), a member of the WHO working group, argues that “pathologising language is associated with stigma, discrimination and with human rights violation in medical settings”; therefore, he engages in battles to change the pathologising language in the ICD. He lobbies for changing the words such as abnormality, disorder, and malformation to variation. However, the WHO does not have the power to impose treatments. Rather, the international standards influence national and institutional protocols. Depending on the country or the hospital, the protocols might vary but are, for most parts, rooted in the international consensus. With national or institutional protocols comes a double discourse. This, for example, is visible in Carpenter’s (2018) article and the letters he received from the Chief and Health Minister of the ACT. It was also mentioned by Davis (Personal communication, 20. April 2020) who claims that parents, medical professionals and students do not automatically link the human rights violations they hear happening to intersex people and the DSD conditions and syndromes they encounter. This double discourse is also found at the WHO, whose legal department holds a human rights discourse, but whose department responsible for the ICD continues to pathologise variations in its newest version. This double discourse creates a difficult situation for intersex organisations as many are reluctant to use DSD language as it goes against their core values. While the language of DSD, VSC and intersex encompass the same individuals, medical institutions refuse to use intersex or even, in some cases VSC. These terms are, in their eyes, political, refer to an identity or are stigmatising.

In practice, different conflicts arise: medical professionals not making the link between DSD and intersex, parental distress, and strong hierarchical ties in the medical complex. While the first type of conflict has been discussed, parental distress surely is an essential reason for treatments, but also stems from pathologisation of VSC and the disciplinary-power medicine holds. In a study conducted by Dr Jürg Streuli (2013), a member of the DSD team at the children's hospital in Zurich, found out that of a pool of hypothetical parents who chose surgery for their hypothetical child with a VSC, 66% had watched a medicalised video, while only 23% of them had watched a demedicalised one. This shows the authority medical professionals have on parental distress and decision-making with the language and setup used. Lastly, the medical institution is hierarchical. Daniela Truffer and Markus Bauer from StopIGM.org (Personal communication, 8 May 2020) call out this academic complicity. The organisation claims that for a young doctor or aspiring academics who want to advance their careers, it is risky to speak against surgeries. The organisation's representatives claim that it is for that reason that the few allied doctors tend to be at the end of their career.

> Intersex is not taught in medical schools here in Finland; I did not read about it in magazines and things like that. It just came from the bushes to me […] As a paediatric surgeon, I was trained to do the diagnostic work with cases of ambiguous genitalia, because it is a team of doctors and paediatric surgeons in Finland are part of that team. When I was training to become a paediatric surgeon, I was also taught how to do these, let's say, corrective cosmetic surgeries, and at that time it was not allowed to criticise your elders, and it was impossible to voice out my thoughts on this. When I was doing my first intersex surgeries due to cosmetic reasons, I felt like it was such a huge human rights violation and especially a children's rights violation that I swore I would never do this, when I am independent and can decide for myself. And I never done it since then. (Bonobo3D, 2013)

In this statement from 2013, Mika Venhola, Paediatric Surgeon from Oulu University Hospital in Finland, illuminates the vicious circle and the problems around the care of VSC and the awareness of doctors about intersex human rights. Medical schools do not teach about intersex issues, but do instruct students to perform corrective surgeries and diagnosis. Again, by using diagnostic language or DSD, doctors escape human rights criticism. Ins A. Kromminga (Personal communication, 21 May 2021) remembers talking to Venhola during the third IIF and the doctor telling them that change in hospitals is going to be difficult to occur because of the hierarchical system. Betsy Driver (Personal communication, 26 April 2020) also shared similar discussions, but with medical students. After she facilitated a training on intersex and human rights in a medical university, students came up to her and told Driver that her claims were right, that these surgeries should not be done. However, the students claimed, as she recalls, that the medical complex will not change as such. Operations and treatments on intersex children are accepted and in control of people who are routinely doing them.

As illustrated in Figure 3, the last step is ignorance and parental distress as a result of this hierarchy. However, this is influenced by politics and the work of the national, regional or global IHRM. The question, however, remains: how can the IHRM tackle medical institutions and make real change happen?

Chapter 6. Conclusion

To conclude this paper, it is safe to claim that the intersex movement has been continuously evolving since 1993. Whether it was through the organisation of protests, a collaboration with medical professionals or by using the human rights system to protect the bodily integrity of children, the movement has faced various challenges but also successes. Coming from secrecy, trauma and shame and attacking one of the most powerful institution has been, and still is, challenging, burdensome and complicated. To invite health specialists to hear their demands, ISNA changed strategy and language with the hope that this could lead to positive changes and protect the children from unwanted and unnecessary sexual operations. However, this strategy seems to have failed as it reasserted medical power over bodies that do not fit typical definitions or expectations of male or female. Furthermore, the adoption of the DSD language made human rights claim more difficult to apply concretely. With two institutions speaking about the same people but using different terminologies, it is difficult for activists, human rights institutions and governments to assess, quantify and understand the human rights violations happening. How can or should the movement evolve in the coming years to efficiently, rightfully and successfully protect the bodily integrity and right to self-determination of children? How can the international and regional recommendations be turned into national jurisdictions?

The methodology used in this paper, and especially the problem-centred interviews have led to exciting and enriching discussions. The role of the Consensus statement and especially the political or militant atmosphere at the time could be highlighted, and patterns could be drawn. While it seems that ISNA, OII or other activists shared common goals, the main areas of opposition result in the organisational trajectory and strategy that has been used. The role of medical professionals in intersex human rights activism, for example, is one area where activists seem to have different outlooks. After the Chicago conference and ISNA's drastic change in approach, mistrust has been built in the movement towards medical establishments and patient group activists. Needless to write that the fact that medical professionals are the centrepiece of opposition to intersex activism and have tortured, mutilated, operated or discriminated some intersex activists during their infancy, childhood, or later in life, increases the level of mistrust. I believe that the fact that I am an intersex person has positively affected my research and the data that came out of the discussions. I have had the feeling that the participants have trusted me and shared valuable information, archives and statements with me throughout the interview. In some cases, I even received documents and further data afterwards. Another example of activists sharing different points of view regards the role of the LGBT community in intersex activism. One possible reason is that from the 1990s, the LGBT community has participated in the politicisation of the term intersex. While this brought some visibility and to some regards, created a breach in the medical authority, as Davis (2015; Personal communication, 20. April 2020) argues, it also made medical professionals more reluctant to engage with intersex activists. Since ILGA took over intersex in its mandate in 2008, the LGBT community has helped the global IHRM emergence, through financial help and capacity building activities such as the IIF. Meanwhile, some intersex advocate regret, that through the institutionalisation of intersex in the LGBT community, the political demands are less revolutionary and focus more on gender identity rather than harmful medical practices.

The role of international collaboration since 2003, and especially since 2011, has been essential in the professionalisation of the IHRM globally. However, it ought to be stated that most activists interviewed for this research are white and come from industrialised or Western countries. It would be essential to hear the voices of activists in the Global South and their perception and role in the transformative process of intersex activism. Despite activists coming from all continents to the IIF, a majority was European or from the USA. The lack of representation from other regions might have influenced the framing of the demands and discussions. Additionally, it would be interesting for future research to focus more on the connections between the intersex and the disability movement. As discussed in this paper, the medicalisation and pathologisation of both groups might have similarities. Also, both see in the medical complex an opposition, and their discourse might lack in credibility due to patient/sick status.

Bibliography

A step forward for intersex visibility and human rights. (2015). Retrieved from https://www.ohchr.org/EN/NewsEvents/Pages/Astepforwardforintersexvisibility.aspx

Alm, E. (2010). Contextualising intersex: ethical discourses on intersex in Sweden and in the US. *Graduate journal of social science, 7*(2), 95-112

Annual Reports and Documents. (n.d.). Retrieved from https://ilga.org/about-us/annual-reports-documents

Bastien Charlebois, J, (2017) Les sujets intersexes peuvent-ils (se) penser ? Les empiétements de l'injustice épistémique sur le processus de subjectivation politique des personnes intersex(ué)es. *La nouvelle revue des sciences sociales,* (9), 143-162. https://doi.org/10.4000/socio.2945

Bastien Charlebois, J. (2016). De la lourdeur d'écrire un article universitaire sur les enjeux intersexes lorsqu'on est soi-même intersexe. Observatoire des transidentités. Retrieved from https://www.observatoire-des-transidentites.com/tag/intersexe/?fbclid=IwAR2hN3Sn1CbdcIIi9sh9TGe_ztIeqkBT13IQtBxJH3FRT_sc-ekFULxzWWA

Barak, G. (2015). Social justice and social inequalities. *International encyclopedia of the social & behavioral sciences*, (2), 392-396. https://doi.org/10.1016/B978-0-08-097086-8.45085-3

Bonbobo3D. (2013, 9th April). Paediatric surgeon Mika Venhola on intersex [Video]. Youtube. https://www.youtube.com/watch?v=riNtxjntqZE&t=17s

Brockmann, T. (1976). Experiential knowledge: a new concept for the analysis of self-help groups. *Social service review, 50*(3), 445-456. https://doi.org/10.1086/643401

Brown, P., Zavestoski, S. (2004) Social movements in health: an introduction. *Sociology of health and illness,* 26(6), 679-694. https://doi.org/10.1111/j.0141-9889.2004.00413.x

Carpenter, M. (2018). The 'normalisation' of intersex bodies and 'othering' of intersex identities. *Journal of bioethical inquiry, 15*(7), pp. 445-514. doi: 10.1007/s11673-018-9855-8

Caldéron, J. (2004). Lessons from an activist intellectual: participatory research, teaching, and learning for social change. *Latin American perspectives, 31*(1), 81-94. https://doi.org/10.1177/0094582X03259905

Cameron, C. (2014). The disabled people's movement. In C. Cameron (Eds.), *Disability studies: a student's guide*. New York: SAGE Publication http://dx.doi.org/10.4135/9781473957701

Chase, C. (1998). Hermaphrodites with attitude: mapping the emergence of intersex political activism. *Lesbian and gay studies, 4*(2), 189-211. https://doi.org/10.1215/10642684-4-2-189

Chase, C. (1999). Rethinking treatments for ambiguous genitalia. *Pediatric Nursing, 25*(4), 451-455. https://pubmed.ncbi.nlm.nih.gov/12024368/

Chase, C. (2002a). "Cultural practice" or "reconstructive surgery"? U.S. genital cutting, the intersex movement and medical double standards. In S. James & C. Robertson (Eds.), *Genital cutting & transnational sisterhood: disputing U.S. polemics* (pp. 126-151). Champaign: University of Illinois Press.

Chase, C. (2002b, May). What is the agenda of the intersex patient advocacy movement?. *Prepared for the First World Congress: hormonal and genetic basis of sexual differentiation disorders*, Temp Arizona

Colpatino, J. (1997, 11th December). The case of Joan/John. The Rolling Stones magazine, pp.54-97.

Concluding observations on the seventh periodic report of Switzerland. (2015). Retrieved from https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/201/51/PDF/G1520151.pdf?OpenElement

Concluding observations on the combined second to fourth periodic reports of Switzerland. (2015). Retrieved from http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhskw6ZHlSjLETdRql6Pfo3d19G0fwi7ZPZdEOVKAQgeqWKogX2iXEvcG5O%2BzGKtEo1nvnVtG%2FXYEnmWa47plmDxnXlhPMHh5Fz%2FKc%2FL6gvzos

Concluding observations on the initial report of Germany. (2015). Retrieved from https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/096/31/PDF/G1509631.pdf?OpenElement

Conrad, P., Schneid, W. (1992). *Deviance and medicalization: from badness to sickness.* Philadelphia: Temple University Press.

Conrad, P. (2007). *The medicalization of society: on the transformation of human conditions into treatable disorders*. Baltimore: Johns Hopkins University Press

Constitution of ILGA. (2019). Retrieved from https://ilga.org/downloads/ILGA_World_Constitution_2019.pdf

Council of Europe (2015). *Human rights and intersex people. Issue paper*. Strasbourg: Council of Europe

Cools, M., Simmonds, M., Elfold, S., Gorter, J., Ahmed, S. F., D'Alberton F. et al. (2016). Response to the Council of Europe Human Rights Commissioner's issue paper on human rights and intersex people. *European Urology*, (70), 407-409. https://doi.org/10.1016/j.eururo.2016.05.015

Crenshaw, K. (1991). Mapping the margins: intersectionality, identity politics, and violence against women of color. *Stanford law review, 43*(6), 1241-1300. DOI: 10.2307/1229039

Crochetti, D., Arfini, E. A., Monro, S., Yeadon-Lee, T. (2020). 'You're basically calling doctors torturers': stakeholder framing issues around naming intersex rights claims as human rights abuses. *Sociology of health & illnesses, 42*(4), 943-958. https://doi.org/10.1111/1467-9566.13072

Curtis. (2007). Why we do not use "Disorder of Sex Development". OII Intersex Network. Retrieved from http://oiiinternational.com/697/why-we-do-not-use-disorder-of-sex-development/

Darbelley, F. (2014). Rethinking inter- and transdisciplinary: undisciplined knowledge and the emergence of a new thought style. *Futures,* (65), 163-174. https://doi.org/10.1016/j.futures.2014.10.009

Davis, G. (2015). *Contesting intersex: the dubious diagnosis*. New York: NYU Prss

Dreger, A. (2018). Twenty years of working toward intersex rights. *Bioethics in action*, 55–73. DOI:10.1017/9781316343197.004

Ehrenreich, N., Barr, M. (2005). Intersex surgery, female genital cutting, and the selective condemnation of 'cultural practices'. *Harvard civil rights-civil liberties law review, 40*(70), 71-140. https://ssrn.com/abstract=2926589

Epstein, S. (2007). Patient groups and health movements. In E. J. Hackett, O. Amsterdamska, M.E. Lynch, J. Wajcman (Eds.), *The handbook of science and technology studies: 3rd Ed.* (pp. 499-540). Cambridge: MIT Press

Equality Works. (2011). Forum on intersex organising. [Archive]

Fact sheet intersex. (n.d.). Retrieved from https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf

Fassin, D. (2000). Entre politiques du vivant et politiques de la vie. Pour une anthropologie de la santé. *Anthropologie et sociétés, 24*(1), pp. 95-116. https://doi.org/10.7202/015638ar

Fassin, D. (2011). This is not medicalization. In G. Hunt, M. Milhet, H. Bergerin (Eds.), *Drugs and culture: knowledge, comsumption and policy* (pp. 85-93). Farnham: Ashgate Publishing

First ever international intersex forum. (2011). Retrieved from https://ilga-europe.org/what-we-do/our-advocacy-work/trans-and intersex/intersex/events/first-ever-international-intersex

Foucault, M. (1974/1997). Technologies of the self (Translated by Robert Hurley). In P. Rabenow (Eds.), *Michel Foucault, ethics, subjectivity and the truth: the essential work of Foucault 1954-1984* (pp. 223-252). New York: The New York Press

Foucault, M. (1976/1978). *The history of sexuality: an introduction Vol.1* (Translated by Robert Hurley). New York: Pantheon Books

Foucault, M. (1976/1980). Truth and power (Translated by Colin Gordon). In C. Gordon (Eds.), *Power/knowledge: selected interviews and other writings 1972-1977*(pp. 109-133). New York: The New Press.

Foucault, M. (1984/1997). The ethics of the concern of the self as a practice of freedom (Translated by Robert Hurley). In P. Rabenow (Eds.), *Michel Foucault, ethics, subjectivity and the truth: the essential work of Foucault 1954-1984* (pp. 281-302). New York: The New York Press

Foucault, M. (1982). The subject and power. *Critical inquiry, 8*(4), 777-795. www.jstor.org/stable/1343197

Fricker, M. (2007). *Epistemic injustice: power & the ethics of knowing*. Oxford: Oxford University Press.

Garland, F., Travis, M. (2020). Making the state responsible: intersex embodiment, medical jurisdiction, and state responsibility. *Journal of law and society, 47*(2), 298-324. https://doi.org/10.1111/jols.12223

Guillod, V. (2008). Intersexe: ne pas avoir le droit de dire ce qu'on ne nous a pas dit que nous étions. *Nouvelles Questions Féministe, 27*(1), 37-48

Häkli, J., Kallio, K.P. (2018) On becoming political: the political in subjectivity. *Subjectivity,* (11), 57–73. https://doi.org/10.1057/s41286-017-0040-z

Hampson, J. G. (1955). Hermaphroditic genital appearance, rearing and eroticism in hyperadrenocorticism. *Bulletin of the Johns Hopkins Hospital, 96*(6), 265–273. https://pubmed.ncbi.nlm.nih.gov/14378808/

Hampson, J. G., Money, J., Hampson, J. L. (1956). Hermaphrodism: recommendations concerning case management. *The Journal of clinical endocrinology and metabolism, 16*(4), 547–556. https://doi.org/10.1210/jcem-16-4-547

Hanson, K. & Nieuwenhuys, O. (2013). Living rights, social justice, translation, in K. Hanson & O. Nieuwenhuys (Eds.), *Reconceptualizing children's rights in international development. Living rights, social justice, translations* (pp. 3-25). Cambridge : Cambridge university press

Hanson, K. Vandaele, A. (2013) Translation working children's rights in international labour law. In Hanson, K. Nieuwenhuys, O. (Eds.), *Recontextualizing children's rights in international development: Living rights, social justice and translations* (pp. 250-271). Cambridge: Cambridge Press.

Hanson, K., Lundy, L. (2017). Does exactly what it says on the tin? A critical analysis and alternative conceptualisation of the so-called "general principles" of the Convention on the Rights of the Child. *International journal of children's rights. 25*(2), 285-306. https://doi.org/10.1163/15718182-02502011

Hausman, B. L. (2000). Do boys have to be boys? gender, narrativity, and the John/Joan case. *NWSA journal, 12*(3), 114-138. https://doi.org/10.2979/NWS.2000.12.3.114

Hayes, J., Hannold, E. M. (2007). The road to empowerment: a historical perspective on the medicalization of disability. *Journal of health and human service administration, 30*(3), 352-377.

Holmes, M. (2000). Queer cut bodies. In J. A. Boone, M. Dupuis, M. Meeker, K. Quimby, C. Sarver, D. Silverman, & R. Weatherstone (Eds.), *Queer frontiers. Millennial geographies, genders, and generations* (pp. 84–110). Madison: University of Wisconsin Press.

Holmes, M. (2008). Mind the gaps: intersex and (re-productive) spaces in disability studies and bioethics. *Bioethical inquiry*, (5) 169-181. https://doi.org/10.1007/s11673-007-9073-2

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. https://doi.org/10.1136/adc.2006.098319

Human Rights Commission of the City of San Francisco. (2005, April 28). *A human rights investigation into the medical "normalization" of intersex people*. San Fransisco

I'Anson, J., Quennerstedt, A., & Robinson, C. (2017). The International economy of children's rights: Issues in translation. *International journal of children's rights,* (25), 50-67. https://doi.org/10.1163/15718182-02501004

ILGA Europe (2011). Annual report 2010-2011. Retrieved from https://www.ilga-europe.org/sites/default/files/Attachments/annual-2010-2011.pdf

ILGA World member organisations (n.d.) Retrieved from: https://ilga.org/member-organisations

Intersex Network. (n.d.). Retrieved from http://oiiinternational.com/

ISNA (2008). Dear friends and supporters. Retrieved from https://isna.org/

Karkazis, K. (2008). *Fixing sex: intersex, medical authority and lived experience*. Durham: Duke University Press

Karkazis, K., Tamara-Mattis, A., Kon, A. (2010) Genital surgery for disorders of sex development: implementing a shared decision-making approach. *Journal of pediatric endocrinology & Metabolism, 23*(3), 789-806. doi: 10.1515/jpem.2010.129.

King, M. L. (2010). *Why we can't wait*. Boston: Beacon Press

Köppel, U. (2016). Zur Aktualität kosmetischer Operationen „uneindeutiger" Genitalien im Kindesalter. *Zentrum für transdisziplinäre Geschlechterstudien*. Berlin: Humboldt-Universität zu Berlin

Lazzarato, M. (2002). Du biopouvoir au biopolitique. *Multitudes, 1*(1), 45-57. DOI:10.3917/mult.001.0045.

Lilja, M., Vinthagen, S. (2014). Sovereign power, disciplinary power and biopower: Resisting what power with what resistance. *Journal of political power, 7*(1). DOI: 10.1080/2158379X.2014.889403

Marshall, V. (1954). True hermaphroditism: a conference on the management of one patient. *The journal of urology, 72*(1), 77-86. https://doi.org/10.1016/S0022-5347(17)67545-1

Merrick, T. (2019). From 'Intersex' to 'DSD': a case of epistemic injustice. *Synthese*, (196), 4429–4447. https://doi.org/10.1007/s11229-017-1327-x

Medina, J. (2017). Varieties of hermeneutical injustice. In Kidd, J.I., Medina, J., Pohlhaus, G (Eds.), *The routledge handbook of epistemic injustice* (pp. 41-52). New York: Routledge.

Merry, S. E., Peggy, L., Rosen, M. Ş., Yoon, D. H. (2010) Law from below: women's human rights and social movements. *New York City law & society review, 44*(1), 101-128. https://doi.org/10.1111/j.1540-5893.2010.00397.x

Monitoring the core international human rights treaties. (n.d). Retrieved from https://www.ohchr.org/EN/HRBodies/Pages/Overview.aspx

Neveu, E. (2005). *Sociologie des mouvements sociaux*. Paris: La Découverte

Nieche, R (2013). Foucault, counter-conduct and school leadership as a form of political subjectivity. *Journal of educational administration and history, 45*(2), 144-158, https://doi.org/10.1080/00220620.2013.768968

O'Brian, M. (2009) A problem of disorder. OII intersex network. Retrieved from http://oiiinternational.com/705/a-problem-of-disorder/

Open letter: A call for the inclusion of human rights for intersex people. (2012). Retrieved from https://www.ilga-europe.org/sites/default/files/hrd_2012_-_intersex_forum_-_un_navil_pillay_letter_2012.pdf

Opening remarks by Zeid Ra'ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert meeting on ending human rights violations against intersex persons. (2015). Retrieved from https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431

Our Mission. (n.d.). Retrieved from https://www.accordalliance.org/about-accord-alliance/our-mission/

Poretti, M. (2019) Recherche qualitative impliquant les enfants: approches, méthodes, outils. (SA 2019 - Méthodologie et éthique de la recherche en droits de l'enfant) [PowerPoint Presentation] Bramois : University of Geneva. Retrieved from https://moodle.unige.ch/

Public Statement by the African intersex movement. (2017). Retrieved from https://www.astraeafoundation.org/stories/public-statement-african-intersex-movement/

Reiter, M. (1998). Zur Spiegelung des nekrophilen Selbst am Sündenbock: eine begriffliche Annäherung. [Archive]

Reiter, M. (1999). "Menschen denken polar, die Natur ist es nicht." Geschlecht als sozialer Code: Intersexualität zwischen Widerstand und Auslöschung. *Zeitschrift für politische Psychologie,* (7), 37-54

Rink, R.C., Szymanski, K.M. (2015). Disorders of sexual development: surgical management. In: Lima M., Manzoni G. (Eds.), *Pediatric urology*. Milano: Springer

Sacket, D. (1997). Evidence-based medicine. *Seminars in perinatology, 12*(1), 3-5. https://doi.org/10.1016/S0146-0005(97)80013-4

Schain, W.S. (1980). Patients' rights in decision making: the case for personalism versus paternalism in health care. *Cancer,* (46), 1035-1041 https://pubmed.ncbi.nlm.nih.gov/7397654/

Scholl, J. (2017). The muddle of medicalization: pathologizing or medicalizing?. *Theoretical medicine and bioethics, 38*(4), 265-278. DOI: 10.1007/s11017-017-9414-z

Simpson, L. (2017). Epistemic and political agency. In Kidd, J.I., Medina, J., Pohlhaus, G (Eds.), *The routledge handbook of epistemic injustice* (pp. 254-260). New York: Routledge.

Simpson, R. G. (1996). Relationships between self-help health organizations and professional health care providers. *Health and social care in the community, 4*(6), 359-370. https://doi.org/10.1111/j.1365-2524.1996.tb00083.x

Streui, J. C., Vayena, E., Cavicchia-Balmer, Y., Huber, J. (2013). Shaping parents: impact of contrasting professional counseling on parents' decision making for children with disorders of sex development. *The journal of sexual medicine, 10*(8), 1953-1960. https://doi.org/10.1111/jsm.12214

Tarrow, S. (1996). Social movements in contentious politics: a review article. *American political science review, 90*(4), 874-883. https://doi.org/10.2307/2945851

The Associated Press. (2004, 12th March). David Reimer, 38, subject of the John/Joan case. The New York Times. Retrieved from https://www.nytimes.com/2004/05/12/us/david-reimer-38-subject-of-the-john-joan-case.html

The Moscow statement (Statement of the Russian intersex community). (2020). Retrieved from https://www.intersexrussia.org/statement-eng?fbclid=IwAR0RufNFH9xBwPLTJHLxu7uTogasGnMTAERWXFuSxSTr5n_NJBIW9xNA5Ys

Thomas, B. (2007). Die Chicago Konsensus Konferenz 2005 aus der Sicht einer Patientin. *Zeitschrift für Sexualforschung, 20*(2): 186-193. doi: 10.1055/s-2007-960679

Tilly, Charles. (1978). *From mobilization to revolution*. McGraw-Hill College

Tilly, C. (1993). Social movements as historically specific clusters of political performances. *Journal of sociology,* (38), 1-30). www.jstor.org/stable/41035464

Geneva institutions of higher education. (2019). Code of ethics and professional conduct for the Geneva institutions of higher education. Retrieved from https://www.unige.ch/ethique/files/1915/7548/0988/CharteEthique-105x210-2019-Web-EN.pdf

Vienna 2008. (s.d.). Retrieved from https://www.ilga-europe.org/conference/annual-conferences-2010-and/vienna-2008

Vilora, H. (2017). *Born both: an intersex life*. New York: Hachette Books

Wanderer, J. (2017). Varieties of testimonial injustice. In Kidd, J.I., Medina, J., Pohlhaus, G (Eds.), *The routledge handbook of epistemic injustice* (pp. 27-40). New York: Routledge.

Welcome singular they. (2019). Retrieved from https://apastyle.apa.org/blog/singular-they#:~:text=APA%20endorses%20the%20use%20of,use%20the%20singular%20%E2%80%9Cthey.%E2%80%9D

What is ILGA-Europe. (n.d.). Retrieved from https://www.ilga-europe.org/who-we-are/what-ilga-europe

Williamson, C. (2008). The patient movement as an emancipation movement. *Health expectations, 11*(2), 102-112. doi: 10.1111/j.1369-7625.2007.00475.x

Witzel, A. (2000). The problem-centered interview. *Forum qualitative Sozialforschung / Forum: Qualitative Social Research, 1*(1), Art. 22, Retrieved from http://nbn-resolving.de/urn:nbn:de:0114-fqs0001228

Witzel, A., Reiter, H. (2012) *The problem-centred interview*. SAGE Publications Ltd

Young, H. (1936). Discussion: the abnormalities and plastic surgery of the lower urogenital tract. *The journal of urology, 35*(4), 417-475. https://doi.org/10.1016/S0022-5347(17)72209-4

Zola, I. K. (1972). Medicine as an institution of social control. *Health, 41*(251), 210-214. https://doi.org/10.1111/j.1467-954X.1972.tb00220.x

2nd International Intersex Forum. (2012). Retrieved from https://ilga-europe.org/what-we-do/our-advocacy-work/trans-and-intersex/intersex/events/2nd-international-intersex-forum

3rd International Intersex Forum. (2013). Retrieved from https://www.ilga-europe.org/resources/news/latest-news/3rd-international-intersex-forum-concluded

Annexe

A: Statement 1st IIF

The Forum agreed on the demands aiming to end discrimination against intersex people and to ensure the right of bodily integrity and self-determination:

1. To put an end to mutilating and 'normalising' practices such as genital surgeries, psychological and other medical treatments, including infanticide and selective abortion (on the grounds of intersex) in some parts of the world.
2. 2. To ensure that the personal, free, prior, and fully informed consent of the intersex individual is a compulsory requirement in all medical practices and protocols.
3. Creating and facilitating supportive, safe and celebratory environments for intersex people, their families and surroundings.

(*First ever international intersex forum*, 2011)

B: Statement 2nd IIF

The Forum agreed to affirm the principles of the first International Intersex Forum and extended the demands aiming to end discrimination against intersex people and to ensure the right of bodily integrity and self-determination:

1. To put an end to mutilating and 'normalising' practices such as genital surgeries, psychological and other medical treatments, including infanticide and selective abortion (on the grounds of intersex).
2. To ensure that the personal, free, prior, and fully informed consent of the intersex individual is a compulsory requirement in all medical practices and protocols.
3. Creating and facilitating supportive, safe and celebratory environments for intersex people, their families and surroundings.
4. In view of ensuring the bodily integrity and health of the intersex child, psycho-social support and non-pathologising peer support be provided to parents and/or care providers and the child`s immediate family instead of surgical or other medical treatment unless such interventions are live-saving.
5. The provision of all human rights and citizenship rights to intersex people.
6. The provision of access to one`s own medical records and any documentation, and the affirmation of the intersex person`s right to truth.
7. The acknowledgement and redress of the suffering and injustice caused in the past.

In view of the above the Forum calls on:

1. The United Nations to take on board intersex rights in its human rights work. Find the open letter to the UN Commissioner for Human Rights here.
2. Other regional and national human rights institutions to address the human rights of intersex people in their work and in turn call on their respective governments/institutions to affirm them.
3. Human rights organisations and LGBTI specific organisations to give visibility and inclusion to intersex people and their human rights concerns.
4. Intersex people to link up to the intersex movement and help it become more visible.

(*2nd Intersex Forum,* 2012)

C: Malta declaration

Preamble:

We affirm that intersex people are real, and we exist in all regions and all countries around the world. Thus, intersex people must be supported to be the drivers of social, political and legislative changes that concern them.

We reaffirm the principles of the First and Second International Intersex Fora and extend the demands aiming to end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination.

Demands:

1. To put an end to mutilating and 'normalising' practices such as genital surgeries, psychological and other medical treatments through legislative and other means. Intersex people must be empowered to make their own decisions affecting own bodily integrity, physical autonomy and self-determination.
2. To put an end to preimplantation genetic diagnosis, pre-natal screening and treatment, and selective abortion of intersex foetuses.
3. To put an end to infanticide and killings of intersex people.
4. To put an end to non-consensual sterilisation of intersex people.
5. To depathologise variations in sex characteristics in medical guidelines, protocols and classifications, such as the World Health Organization's International Classification of Diseases.
6. To register intersex children as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender.

7. To ensure that sex or gender classifications are amendable through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.
8. To raise awareness around intersex issues and the rights of intersex people in society at large.
9. To create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings.
10. To ensure that intersex people have the right to full information and access to their own medical records and history.
11. To ensure that all professionals and healthcare providers that have a specific role to play in intersex people's wellbeing are adequately trained to provide quality services.
12. 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.
13. To build intersex anti-discrimination legislation in addition to other grounds, and to ensure protection against intersectional discrimination.
14. To ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family.
15. To ensure that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex. Intersex athletes who have been humiliated or stripped of their titles should receive reparation and reinstatement.
16. Recognition that medicalization and stigmatisation of intersex people result in significant trauma and mental health concerns.
17. In view of ensuring the bodily integrity and well-being of intersex people, autonomous non-pathologising psycho-social and peer support be available to intersex people throughout their life (as self-required), as well as to parents and/or care providers.

In view of the above the Forum calls on:

1. International, regional and national human rights institutions to take on board, and provide visibility to intersex issues in their work.

2. National governments to address the concerns raised by the Intersex Forum and draw adequate solutions in direct collaboration with intersex representatives and organisations.
3. Media agencies and sources to ensure intersex people's right to privacy, dignity, accurate and ethical representation.
4. Funders to engage with intersex organisations and support them in the struggle for visibility, increase their capacity, the building of knowledge and the affirmation of their human rights.
5. Human rights organisations to contribute to build bridges with intersex organisations and build a basis for mutual support. This should be done in a spirit of collaboration and no-one should instrumentalise intersex issues as a means for other ends.

(*3rd international intersex forum*, 2013)