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*Master Thesis*

*“Beyond the binary – Intersex experiences and  
activism in Germany and the Netherlands –  
A decolonial approach”*

*submitted by*

*Leonie Karolin Fischer*

*Master of Science International Development Studies*

*Faculty of Geosciences, Utrecht University*

*Department of Human Geography and Planning*

*Supervisor: Janwillem Liebrand*

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## Abstract

With the birth of a child and the glance between their legs, the child's pathway is often pre-defined from that moment. In the case of intersex children, this pathway is frequently marked by discrimination, non-consensual medical interventions, and secrecy (von Lisdonk, 2014). This research explores the struggles and experiences of intersex individuals in Germany and the Netherlands, focusing on advocacy campaigns. By using a decolonial lens, this research examines how intersex activism challenges colonial and heteronormative structures that, to this day, still impact, marginalise and, dehumanise intersex individuals. By focusing on Germany and the Netherlands, this research questions Europe's position as the centre of colonial thought and practice, illustrating how colonial legacies continue to shape societal norms, affecting the lives of intersex individuals (Adamson, 2022; Ndlovu-Gasheni, 2012). Two different qualitative research methods are used, in-depth interviews and a critical discourse analysis of advocacy documents. While the interviews identify more personal experiences, the discourse analysis gives more insights into key strategies employed by activists (Hennink et al., 2020; Locke, 2004).

The findings reveal, there is a differentiation of emotional and societal struggles for intersex individuals. While societal struggles encompass the lack of legal recognition or non-consensual medical interventions, emotional struggles touch upon topics of guilt, dynamics of community feeling, and coping mechanisms. A human rights lens is the most frequently used framing, while there is little to no usage of a solely medical lens. A big focus of responsibility is thereby laying upon legal advancements, collaborative educational approaches between activists and the medical sector, and community-building efforts rather than confrontational strategies.

Intersex individuals in Germany and the Netherlands face different kinds of struggles that are defined by societal power structures. They strategies through legal, educational, visibility and community-building efforts, focusing on human rights to challenge these structures, enhance agency, and facilitate access to developmental services.

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## List of abbreviations

CDA - Critical discourse analysis

DSD – Disorder/Differences of sex development

FGM - Female Genital Mutilation

IGM - Intersex Genital Mutilation

LGBTQIA+ - Lesbian, gay, transgender, queer, intersex, asexual and more

Trans - Transgender

UN - United Nations

# 1. Introduction

"Is it a boy or a girl?" This question typically asked with high expectations at the birth of a child, carries a deeper, more complex significance for intersex children and their families. In many cultures, the moment of birth, defined by the sex binary, shapes one's identity and life path in many ways (von Lisodonk, 2014, p.15; Karkazis, 2008). However, 1 in 90 individuals of the population is born with features not fitting the typical definitions of male or female bodies (StitchingOpenMind, 2023; Zelayandia-Gonzalez, 2023). The question about a child's gender does not just reflect curiosity but predicts a journey through societal misunderstanding, medical intervention, and often, discrimination (Wolff, Rubin & Lock Swarr, 2022). Notable is that in Germany, the uncertainty of an intersex child's sex characteristics is considered enough reason to perform an abortion up to the 8th month of pregnancy. This happens while findings show that only little intersex variations present health risks (von Molitor, 2015). This underscores the biases and challenges faced by those who differ from binary norms, and the need for advocacy (Carpenter, 2018).

## Problem statement and knowledge gap

In recent years, mostly in Europe, the discourse surrounding gender diversity and intersex rights has increasingly found its place within broader societal, medical, legal, and political conversations. Many intersex advocates across Europe have successfully highlighted the troubles of intersex individuals to major international organisations, including the United Nations and the European Agency for Fundamental Rights. These influential institutions have recognised and publicly addressed the obstacles that intersex individuals encounter. While certain nations have made noticeable progress in revising their policies to better protect intersex rights, a significant number of countries still fall short of acknowledging and addressing the human rights issues associated with being intersex (Paternotte, Hablous & Kraus, 2022). Regardless of this development, there is a gap in the acceptance of other minority groups and individuals with intersex variations (Walker, 2022). This is visible in the continuous execution of medical interventions on intersex children, despite new guidelines being introduced stating that interventions should be avoided until the children themselves can make informed choices (Crocetti, 2019 as cited in Walker, 2022). Additionally, intersex is being picked up under the term of LGBTQIA+ issues, and instrumentalised by right-wing conservatives to serve the purpose of upholding the status quo (Roth, 2015; Warsi & Hastings, 2022; Schotel, 2023).

While there is substantial research on the medical aspects of intersex issues, there is comparatively little research on activism and advocacy. Specifically, the intersection of intersex activism with decolonial theory remains often unexplored (Carpenter, 2016; Rubin, 2015). This research will focus on the struggles and activism of intersex individuals in the Western contexts of Germany and the Netherlands, examining how these intersect with decolonial theory, and therefore, with questions of binary norms, agency and how to move forward in a global context. Germany and the Netherlands are often viewed as progressive and sophisticated countries regarding topics like human rights, gender, and sexuality. However, this research will explore the paradox of their progressive reputations versus the lived realities of intersex individuals, revealing the nuances and complexities of these societies (Schotel, 2023). This will be reached by applying a decolonial lens to the analysis, taking inspiration from Ndlovu-Gasheni (2012), who identifies the “control of gender and sexuality” as one of the four colonial matrices of power (the others being: control of economy, control of authority, and control of subjectivity and knowledge) (2012, p.49). Moreover, this research aims to bridge the gap to understand how decolonial theory applies to specific Western countries. It will examine how these efforts contribute to a global decolonial perspective (Rubin, 2015; Boellstorff et al., 2014). Furthermore, the particular strategies the advocacy campaigns use are yet, in many cases unknown in Europe (Crocetti et al., 2020a). By examining advocacy campaigns for intersex rights, this research will explore their strategies, challenges, and impacts. In doing so, it aims to understand how intersex individuals enhance agency and how their access to developmental services is facilitated, contributing to a deeper understanding of the intersection between intersex issues and decoloniality.

## Development and Scientific Relevance

The predominant societal response to intersex individuals has been to medicalise and pathologise them, often leading to surgical and hormonal interventions aimed at “fixing” a child rather than allowing them to live outside the gender binary (Carpenter, 2018, p.488; Walker, 2022). Based on this, Walker (2022) poses the question of why there hasn’t been more progress in accepting intersex bodies and diversity. By employing a decoloniality lens, this research seeks to understand the structural oppressions rooted in colonial legacies that impact gender, authority, knowledge, and intersubjectivity (Adamson, 2022). To show the developmental relevance, it is critical to question the human rights violations and oppressive structures that intersex individuals have to fight with. The historical impact of colonialism has



ingrained structures of patriarchy, heteronormativity, and a gender binary system, reinforcing current social inequalities (Adamson, 2022). Intersex individuals, by their very existence, highlight these systemic issues and are to this day one of the most impacted groups, facing stigmatisation, and discrimination (Adamson, 2022; Wolff, Rubin & Lock Swarr, 2022). Zelayandia-Gonzalez (2023) states that the norms and structures that arise from colonial legacies often marginalise those who do not conform, making the visibility and advocacy for intersex rights crucial. This shows the scientific relevance of this work, as it contends that the advocacy campaigns for intersex rights are not merely about recognition and rights, but also about challenging and deconstructing colonial frameworks that perpetuate social inequalities.

### Research questions and objectives

This study emerges from recognising the unique struggles faced by intersex individuals, particularly in the Netherlands and Germany. Being from Germany, studying in the Netherlands, and considering myself part of the LGBTQIA+ community, this topic gains particular importance to me. This thesis aims to understand the experiences and struggles of intersex individuals, highlight the advocacy campaigns that strive for their rights, and examine how these campaigns challenge existing norms, and foster societal change. Through this exploration, this thesis aims to contribute to the discourse on human rights, advocating for a reevaluation of normative assumptions that control the understanding of sex and gender in both medical and societal contexts. In addition, understanding the role of agency and subjectivity to move forward. This results in the following leading research question: *“What are the struggles and experiences of intersex people in Germany and the Netherlands, and how do they strategise and campaign to change society?”* To answer this main question, several sub-questions have been formulated:

- 1) What struggles and experiences are intersex individuals currently facing in the Netherlands and Germany?
- 2) What advocacy campaigns are currently taking place in the Netherlands and Germany for intersex rights, and what are their strategies to change society?
- 3) How do advocacy campaigns for intersex rights in the Netherlands and Germany enhance the agency and voice of intersex people?
- 4) How do these campaigns impact access to developmental services and contribute to broader societal change?

While decoloniality and decolonising society, is a theoretical approach this research uses, the interviews have shown that this terminology is not used by activists and intersex individuals themselves. Based on this knowledge, the research question was formulated differently, and the word “change” is used. Nevertheless, the research still follows the developmental potential of researching decolonial attempts in progressive perceived countries.

This defines the research objectives that are formulated to address the leading research question. The study aims to understand the struggles and experiences of intersex individuals in Germany and the Netherlands, delving into how societal norms and medical practices shape their lives, laying a basis for the research (Sub-question 1). Secondly, the study seeks to map the landscape of advocacy campaigns currently active in these countries. This involves identifying key actors, topics, and strategies in the fight for intersex rights and how these campaigns aim to challenge societal norms and structures. Doing so could potentially contribute to a broader project of decolonising society and transforming existing power dynamics and oppressive structures (Sub-question 2). Thirdly, the research examines the ways through which advocacy campaigns enhance agency and voice for intersex individuals (Sub-question 3). Lastly, the study aims to understand how advocacy efforts negotiate access to developmental services for intersex people. This involves investigating the impact of these campaigns on securing medical care, legal recognition, and social acceptance, and how these efforts contribute to the broader goal of decolonising society individuals (Sub-question 4).

## Outline of the thesis

In the following the theoretical framework and literature review will discuss the main concepts and theories, providing an overview of the current knowledge of the topic. This will be followed by the conceptual framework, where the main concepts will be elaborated upon, moving from identifying the problem to highlighting the knowledge gap, and explaining how these concepts are applied in the research. Successive to this, is the methodology which gives an overview of the methods used, as well as central variables and their operationalisation, and a short reflection on limitations and the positionality of the author. The contextual geographical framework will give an understanding of the current state of the art in the Netherlands and Germany. After this, the findings from the in-depth interviews and the critical discourse analysis will be explained, followed by a discussion and conclusion answering the leading research questions.

## 2. Theoretical framework and literature review

### Intersex & Norms

Intersex is an umbrella term for individuals born with physical traits that do not conform to typical societal expectations of male or female bodies. While it often gets considered a medical emergency, intersex traits and bodies are healthy variations of human sex characteristics (OII Europe, 2019; Davis 2015). These variations of bodily sex are diverse including the organisation of sex chromosomes, gonadal differences, genital internal and external morphology, hormonal differences, and pubertal sex characteristics such as breasts and facial hair (Greenberg, 1999). Intersex individuals often face the pathologisation of their bodies, meaning they are frequently subject to surgical or medical treatments and diagnosis (OII Europe, 2019).

This medicalisation of intersex bodies contributes to significant human rights violations and has profound implications for the well-being of intersex individuals (Karkazis, 2008). Most medical interventions are conducted without personal, prior, and fully informed consent. These interventions violate their bodily integrity and often result in psychological trauma. Further, intersex individuals face being made invisible, stigma, structural and verbal discrimination, and a lack of access to relevant medical care. Additionally, they often struggle with the lack of legal recognition of their intersex status. Addressing these issues requires a shift towards respecting bodily integrity, informed consent, and the legal and social recognition of intersex individuals (OII Europe, 2019; Davis, 2015).

Historically, Karkazis (2008) shows that the discourse on sex differences prior to the modern period differed significantly from the contemporary one. While medical interest was present, the topic did not dominate legal or political discussions and only got associated with sexual ambiguity in the 16th century (Daston & Park, 1995). An increasing awareness only set in, when there was a growing concern about the relationship between bodies, gender, and desire, where “hermaphrodites and homosexuals” interfered with the clear distinction of male and female (Karkazis, 2008, p. 40). Since 1950 intersex individuals have been subject to non-consensual cosmetic genital surgery to fit them into the typical classification (Karkazis, 2008).

The described medicalisation of intersex individuals is rooted in norms that enforce binary concepts of sex and gender. Norms are shared expectations and rules that guide behavior within

society (Cislaghi & Heise, 2020). They are embedded in cultural practices and institutional structures, influencing how individuals and groups are perceived and treated. Butler (1990) argues that these norms, which influence how sex and gender are regulated, are socially constructed, and perpetuated through various institutions, including medicine. In the context of intersex individuals, these norms manifest as heteronormativity and the binary model. The binary model dictates what so-called normal male and female bodily characteristics should look like, which traits they should possess, and the parameters of acceptable behaviour for men and women (Karkazis, 2008).

### Decoloniality & the colonial gender system

In 1990, Anibal Quijano introduced the concept of coloniality/decoloniality, marking a crucial moment with the end of the Cold War and the rise of neoliberalism (Mignolo & Walsh, 2018). Decoloniality emerges from the recognition that the global power system is asymmetrical, upheld by structures of colonial power (Ndlovu-Gatsheni, 2013). It revolves around three key concepts. The first is the coloniality of power, revealing the origins of the current global power structure. It emphasises how modernity brought progress to the Euro-American world while imposing imperialism on the non-Euro-American world (Ndlovu-Gatsheni, 2013). The second concept, the coloniality of knowledge, scrutinises who generates knowledge and for what purpose, exposing epistemological issues. It shows how knowledge has been used to support imperialism and colonialism with a Euro-American-centric perspective (Ndlovu-Gatsheni, 2013). The third concept, the coloniality of being, questions how “whiteness” gained ontological significance over “blackness” (Ndlovu-Gatsheni, 2013, p. 12).

Decoloniality is often operationalised in studies on the “colonial matrices of power”, in terms of four levels: economic control through dispossession and military superiority (control of the economy), control of authority, control of gender and sexuality based on Western ideals, and control of subjectivity and knowledge by epistemologically framing African subjectivity as inferior and by implication, Western subjectivity as superior (Ndlovu-Gatsheni, 2012, p.49). This concept - especially the colonial matrices of power that focus on the control of gender and sexuality - provides a lens to understand global power dynamics through these matrices, and how it perpetuates colonial dynamics in development and society (Ndlovu-Gatsheni, 2012). And therefore, how groups like intersex individuals are impacted. This underlines the importance of the geographical context of this work, marking Europe as the heart of colonial thinking (Adamson, 2022).

An analysis of the coloniality of gender is understanding the process of how the Western European heteronormative gender system, differentiates between the “civilized” and the “not-civilized” (Lugones, 2010, p. 743 & 753). In this context, the bourgeois white European man, “a being of civilization, heterosexual, Christian” (Lugones, 2010, p.743), was considered the norm. The categorisation led to a further differentiation, where being recognised in one gender and following the gender roles, if women or men, meant being human while being classified as non-gendered, positioned one as being more exploitable (Lugones, 2010). As Mendoza (2016, p. 18 as cited in Adamson, 2022) notes, the coloniality of gender shows Euromodern gender categorisation as a “dehumanizing practice” that survived colonisation. In this context, intersex struggles can be seen as resistance to the colonial matrices of power. A decolonial answer to restoring the lost humanity and intersubjective agency to those most dehumanised, thus intersex individuals (Adamson, 2022).

### Subjectivity & Agency

Subjectivity challenges the perception that all individuals are entirely separate entities, but rather suggests that all lives inevitably involve other people. Thus, Mansfield proposes that the subject is always connected to something beyond itself, operating at intersections of shared principles (Mansfield, 2000).

The connection to agency can be made by looking at a general perception of agency in feminist theory. Often it is referred to as the capacity and ability of individuals to “have some kind of transforming effect or impact” (McNay, 2016, p.39). Hence, explaining agency as intentional actors, who do something on purpose and obtain with that said exercised agency (Buffington, 2007). However, this oversimplifies the process of agency, while downplaying the central role of culture and social structures that shape and constrain interactions (van Young, 2001). If negating the role of culture in relation to intentions and purposeful actions, the question has to be raised what this means in this context for women or anyone considered deviant such as intersex individuals (Johnson, 2003 cited in Buffington, 2007).

Butler’s (1997) work connects subjectivity and agency to the constructs of sex and gender, offering a framework for intersex struggles and agency. Firstly, any form of agency a person exercises is shaped by social and cultural norms – so-called discourses - that direct how they become recognised subjects within their culture. Butler also recognises that subjectivity is

intertwined with sexing and gendering. The consequence for intersex individuals is that their subjectivity is continuously negotiated within the constraints of societal expectations about sex and gender (McQueen, 2015).

Further, asking intersex individuals to conform to traditional male or female categories. These practices highlight the limitations imposed on intersex individuals' agency, as their bodies and identities are subject to external control and definition (Crocetti et al., 2020b).

However, this doesn't negate their agency but rather situates it within a context of subjection. Intersex individuals may find ways to navigate, resist, or even comply with these norms in ways that reflect their agency. For instance, some intersex individuals might choose to undergo medical procedures to align their bodies with societal expectations as a means of mitigating harm or achieving personal comfort. This choice, while appearing to conform to normative pressures, can still be an expression of agency, reflecting a strategic decision to navigate a challenging social environment. Others might actively resist medicalisation and advocate for bodily autonomy and the recognition of intersex rights, thereby exercising agency through resistance (Crocetti et al., 2020b)

### Activism and Advocacy

Activism is “the capacity for people to act and respond to sociocultural forces in ways that contribute to collective well-being” (Ginwright, 2010, p.85). The role of intersex activism is considered a critical force for challenging and transforming sociocultural norms and policies that marginalise intersex individuals, emphasising its aim for the protection of physical integrity, and the de-normalisation of the gender binary system (Davis, 2015; von Wahl, 2019). Historically, 1990 marked the beginning of a significant rise in voices on the consequences of medical treatments, such as shame and secrecy. Davis (2015) describes it as people with similar experiences being brought together, which positions them to bring change at different levels of action. Davis differentiates between three levels: the “institutional, individual and interactional levels of gender structure” (2015, p.28). He highlights the institutional level as one of the most impactful ones with medical professionals, and family being located there, who support and enforce ideas about gender. Hence, this also being the level at which organisations operate to reach social change, and change in medical care (Davis, 2015).

Crocetti et al. (2020a) underline the differences in perspectives and approaches based on different groups e.g. self-advocacy groups or parent-led organisations. The style of activist actions can vary significantly, characterised by factors like the composition of the group, the

relation to allies, or objectives (Crocetti et al., 2020a). The form of activist actions surrounding intersex rights claims can be sorted into different forms such as “public facing-actions” (e.g. protests and awareness campaigns), or closed groups that offer peer support and “negotiate the role of the ‘patient expert’” (Crocetti et al. 2020a, p. 946).

As a subset of activism, advocacy further reflects on which objectives and framing are used within activism. Advocacy campaigns are efforts aimed at educating society, as well as the legal and medical sectors. Their impacts can influence public policy, societal attitudes, and legal frameworks to promote intersex rights (Greenberg, 2006; Davis, 2015). Bauer et al. (2019) give the example of using long-term data, working with the medical sector, and pushing for a “medical self-reform”, or following the approach of criminalising “non-consensual unnecessary practices” (p.1).

#### The existing developments in intersex activism

Historically, Bauer et al. (2019) reflect that the human rights lobbying strategy has grown for intersex activists in Europe since 2008, speaking of a refocusing of tactics to legal objectives including criminalisation (Crocetti et al. 2020a, p. 946). An example of the first attempt at human rights framing is intersex activists drawing parallels between Female Genital Mutilation (FGM) and Intersex Genital Mutilation (IGM), highlighting the similarities in how both practices aim to eliminate bodily and gender differences to fit within cis-gendered, heterosexual norms. This analogy underscores how Western medical practices perpetuate violence against intersex bodies under the guise of normalisation (Adamson, 2022; Rubin, 2015).

Davis (2015) who focused on the advocacy efforts in the US further analysed a shift from “confrontational mobilisation strategies” such as public protests to “unobtrusive mobilisation strategies” or collaborative approaches, working with medical and all other stakeholders to promote change and offer resources to intersex individuals and families (Davis, 2015, p.49-50). The latter strategy can be again separated into two categories “discursive politics” and “occupy and indoctrinate” tactics (Davis, 2015, p.49). While “discursive politics” has the goal of political change through talking and the production of symbolic materials about the stories of victims (Schmitt and Martin, 1999, p. 369 cited as in Davis, 2015, p. 49-50). The tactics of “Occupy and indoctrinate”, do not publicly challenge binary norms but spread stories of experiences and trauma of intersex individuals to have an impact (Davis, 2015, p.49-50).

Generally, there are critical voices on the collaboration of activist groups with the medical sector due to the history and usage of outdated terminology (Davis, 2015).

An interesting connection to look at is between LGBTQIA+ activist efforts and intersex activism. While Greenberg (2006) underlines that feminist, intersex and LGBTQIA+ organisations must combine their efforts to end norms based on sex and gender roles and that their oppressions stem from the same cultural definitions, and sex categories in identity and autonomy, Bauer et al. (2019, p. 29) has a more critical assessment. The authors argue that there are risks of “appropriation and issue deflection”, regardless of their shared stance on human rights violations. Further, LGBTQIA+ groups struggle with the direct representation of the “I”, and connected medical experiences.



## 2.1 Conceptual framework

The conceptual framework of this research will discuss the interplay between several key variables, using specific conceptual tools. The choice of these tools is informed by their relevance to shed light on the complexities of intersex experiences and strategies to change and in broader terms decolonise society.

### Decoloniality and colonial matrices of power

Decoloniality will be used to understand the experiences of intersex people in Germany and the Netherlands as a marginalised group, which is to this day still one of the most impacted ones by colonial influences. Decoloniality helps to see how colonial power structures have imposed binary gender norms and have been marginalising and pathologising intersex bodies over centuries (Adamson, 2022). This will be reached by utilising the colonial matrices of power by Ndlovu-Gatsheni (2012), especially the matrix of gender and sexuality. This helps to understand how colonialism structured society to ensure the superiority of the Global North using the matrices of power. In this case, e.g. the “re-imagination of family in Western bourgeois terms” or the introduction of “Western-centric education” gives a broader understanding of possible influences and how to dismantle these - or to put it differently find strategies how to decolonise society (2012, p. 49).

### Agency

Regaining agency is both a goal of decoloniality and a tool to decolonise society. According to Lugones, decoloniality offers the possibility of restoring humanity and intersubjective agency to those most dehumanised by the coloniality of gender (Lugones, 2003 as cited in Adamson, 2022, p.309). Understanding agency and subjectivity in relation to sex and gender, especially for intersex individuals, involves recognising the influences of societal norms, as described above by Butler (1997). Thus, reflecting on the question under which conditions intersex people can claim their identities and make choices, whether those choices are compliance with or resistance to normative sex and gender pressures. Additionally, the work will explore how intersex individuals enhance their agency within these constrained environments, focusing on strategies, how they navigate medical and legal systems, advocate for their rights, and build supportive communities (Crocetti et al., 2020b).

## Activism and Advocacy

Activism and advocacy play a central role in this work, as the efforts play a central role in enhancing their agency. Activism and advocacy will be analysed to understand their role in challenging societal norms and reaching more rights and visibility of intersex people. The framework will classify different acts of activism, exploring their objectives, participants, and potential impacts. Understanding how these campaigns are built up involves exploring the language and narratives they use, the strategies they follow to engage the public, and how they frame intersex issues. This approach will also consider the challenges these campaigns face, including resistance from legal, medical, and social systems, in the pursuit of intersex rights and autonomy.

## Critical Discourse Analysis and Framing

Critical Discourse analysis (CDA) offers a powerful tool to uncover underlying power dynamics, or ideologies that are embedded in the discourse surrounding intersex issues (Huckin, 1997; Philippou, 2019). Particularly within the realm of visibility and awareness, CDA can be a tool for understanding how experiences and challenges are communicated (Motschenbacher & Stegu, 2013). Framing can be understood as various elements that are highlighted and given one universal set of meanings. Framing can also change how objects are perceived or understood relating to other elements or the actor (Snow, Vliegthart, Ketelaars, 2019). Incorporating the CDA is central to analysing how intersex advocacy campaigns are framed and their impact on public discourse and perception.

This work tries, by connecting CDA with the concept of agency, to understand how intersex individuals navigate, resist, and comply with societal norms, and how their actions and choices reflect their agency within the constraints of these norms, e.g. in the usage of language. This allows for a deeper exploration of the interplay between discourse, power, and agency in the context of intersex activism (Bernard & Ryan, 2010; Philippou, 2019; Crocetti et al., 2020b).

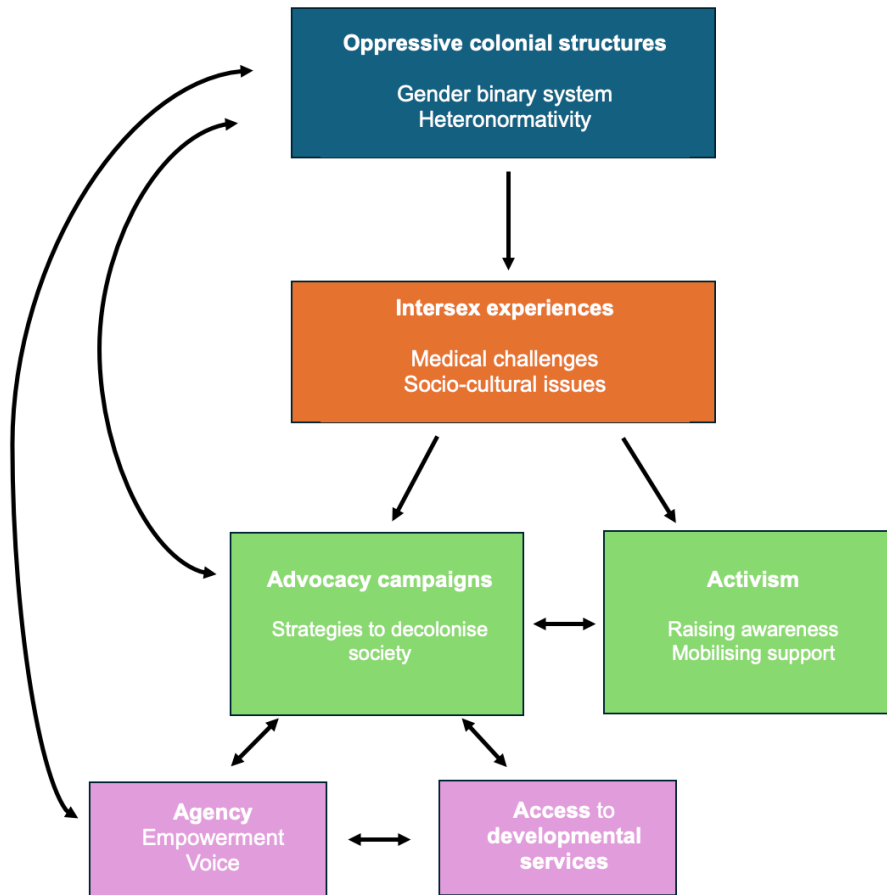


Figure 1 Conceptual framework model, own design

### 3. Methodology

This section will discuss the methodology used to answer the main research question “*What are the struggles and experiences of intersex people in Germany and the Netherlands, and how do they strategise and campaign to change society?*” First, research methods will be explained and justified. Second, the operationalisation of all elements of the conceptual framework will be discussed. This is followed by a description of the data collection and analysis process. Lastly, the positionality of the researcher is reflected upon.

#### 3.1 Methods and Justification

In this research two qualitative methods are used, in-depth interviews and a critical discourse analysis. Employing the method of in-depth interviews is central to capturing diverse narratives and voices. This allows for the exploration of personal experiences, and identifying beliefs, or driving forces behind certain behaviours (Hennink et al., 2020). Another objective of utilising this method is to discover an individual's subjectivity, so factors like identity, that shape a narrative (Wengraf, 2001). Given that intersex is a delicate topic that demands high levels of privacy, in-depth interviews are particularly suitable (Hennink et al., 2020).

While in-depth interviews provide more personal insights, the second method will try to complement the results of the interviews and tie the findings together by analysing texts to understand the social reality around intersex, and how their struggles are made visible. The discourse analysis aims to critically reflect on the discourses that shape our understanding of social reality, which is often evident in the way language is used. This provides the work with more depth and context of strategies, and framing (Huckin, 1997; Hennink et al., 2020). Lastly, observations which were made during the conduction phase provide context to the social settings, and values, providing a better understanding of the findings (Hennink et al., 2020). Table 1 describes the used methods, their goals, and which sub-questions they answered.

*Table 1 Research methods and their corresponding goals and sub-questions*

<b>Main research method</b>	<b>Goal</b>	<b>Question</b>
In-depth interviews	Gathering struggles and experiences of intersex people	Sub-question 1
In-depth interviews / Critical reading / Observations	Identifying advocacy campaigns and strategies	Sub-question 2

In-depth interviews / Critical reading	Understanding how agency and voice is enhanced for intersex people	Sub-question 3
In-depth interviews / Critical reading	Recognise the impact of advocacy campaigns on access to developmental services	Sub-question 4

### 3.2 Operationalisation of the Concepts

The operationalisation of the main concepts involves defining observable variables or indicators that capture the key elements in the research context (Hennink et al., 2020).

Activism can be differentiated in its form, the level and style of action, participants or stakeholders, and objectives (Crocetti et al., 2020a). While advocacy campaigns are a subset of activism, a specific focus is laid upon the measurable dimensions, further specified in Table 2. For this research, four main categories of intersex activism were worked out by the researcher to organise various topical aspects, based on comparable dimensions of activism in the literature (Feder, 2021; Jenzen & Lewin, 2022; Scheadler et al., 2023; Wiesner, 2012). Each category addresses a different aspect of intersex activism, see [Figure 2](#). The categories were used to work out the interview guide, and analytic document, and to later structure findings.

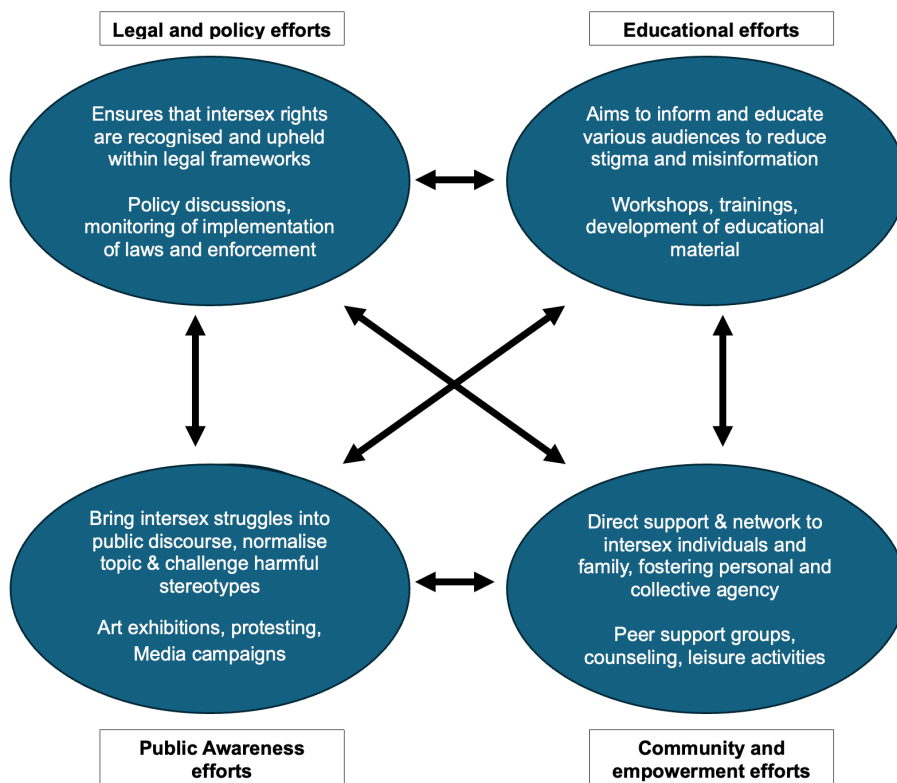


Figure 2 Operationalisation of intersex activism

Agency is a complex construct, as discussed in the literature. Based on this the operationalisation is trying to cover many of these aspects, see Table 2.

Developmental services are a range of medical, psychological, social, and legal services aimed at supporting intersex people across various stages of their lives. Possible providers of these services are medical professionals (e.g. psychologists), counsellors, social workers, legal professionals, or peers (Lampalzer et al., 2021).

*Table 2 Operationalisation of main concepts*

<b>Concept</b>	<b>Definition / Operationalisation</b>	<b>Examples</b>
<b>Advocacy campaigns</b> (Crocetti et al., 2020a; Davis, 2015)	Target groups, Objectives and goals, strategies, framing, impacts	Human rights framing Lobbying of medical institutions, collaboration with legal experts, forming coalitions with self-advocacy groups
<b>Agency</b> (Crocetti et al., 2020b; Scheadler et al. 2023)	Agency involves not just acts of resistance but also subtle forms of navigation within existing power structures	Compliance, Participation, Resistance
<b>Access to developmental services</b> (Lampalzer et al., 2021).	Availability, affordability, acceptability, appropriateness, informed access	Present and reachable, covered by insurance, free from discrimination, evident-based, consent-based, tailored to specific needs

### 3.3 Data Collection

#### 3.3.1 In-depth interviews

In total 14 in-depth interviews were conducted from February 2024 to the end of May 2024 in the Netherlands and Germany. The duration of the interviews ranged from 60 to 120 minutes.

#### Search criteria participants and sampling

A purposive sampling method was used. This involved intentionally choosing participants who possess specific traits crucial to the research, as the qualitative method aims for an in-depth, contextual understanding of intersex experiences (Hennink et al., 2020). Following an inductive approach to the sampling allowed for a flexible process to ensure the topic's diversity

is adequately represented, refining the sample step by step (Hennink et al., 2020). This approach resulted in a smaller, yet more focused sample size of 14 participants. The interviewees are further described in **Fehler! Verweisquelle konnte nicht gefunden werden.**

### The setting and structure of the interview

The interviews were conducted in individual settings, due to the sensitivity of the topic, mainly in places where interviewees felt safe. The interviews were semi-structured, meaning there was a predefined set of questions, based on the interviewee’s background and expertise. Nevertheless, the format allowed for flexibility and open-ended exploration of the interviewee's responses (Hennink et al., 2020). A more detailed structure of the interviews (C), the interview guide and the ethical consent form (A and B), can be found in the Appendix.

### Codes

The transcribed and anonymised interviews were coded. Hennink et al. (2020) describe codes “as issues, topics or concepts that are present in data” (p.323). Firstly, deductive worked-out codes were used, which are based on the theoretical concepts described in section 2 in the theoretical framework, see Table 3.

*Table 3 Deductive codes*

<b>Activism</b>	<b>Challenges</b>	<b>Strategies</b>	<b>Other objectives</b>
Advocacy campaigns	Medical	Community & Empowerment	Agency & voice
Main goals	Political & Legal	Knowledge & Education	Trade-offs
Framing	Societal	Legal & Policy engagement	Intersectionality
Positionality	Norms	Public awareness	Access dev. services

The deductive coding was followed by inductive coding. By active reading, critical thinking, reflecting on data and context, comparing, and making connections, the inductive codes were worked out (Hennink et al., 2020). In addition to the codes important information was noted down. In Figure 3 examples are given of how the inductive codes were worked out. All inductive codes can be found in **Tables Fehler! Verweisquelle konnte nicht gefunden werden**

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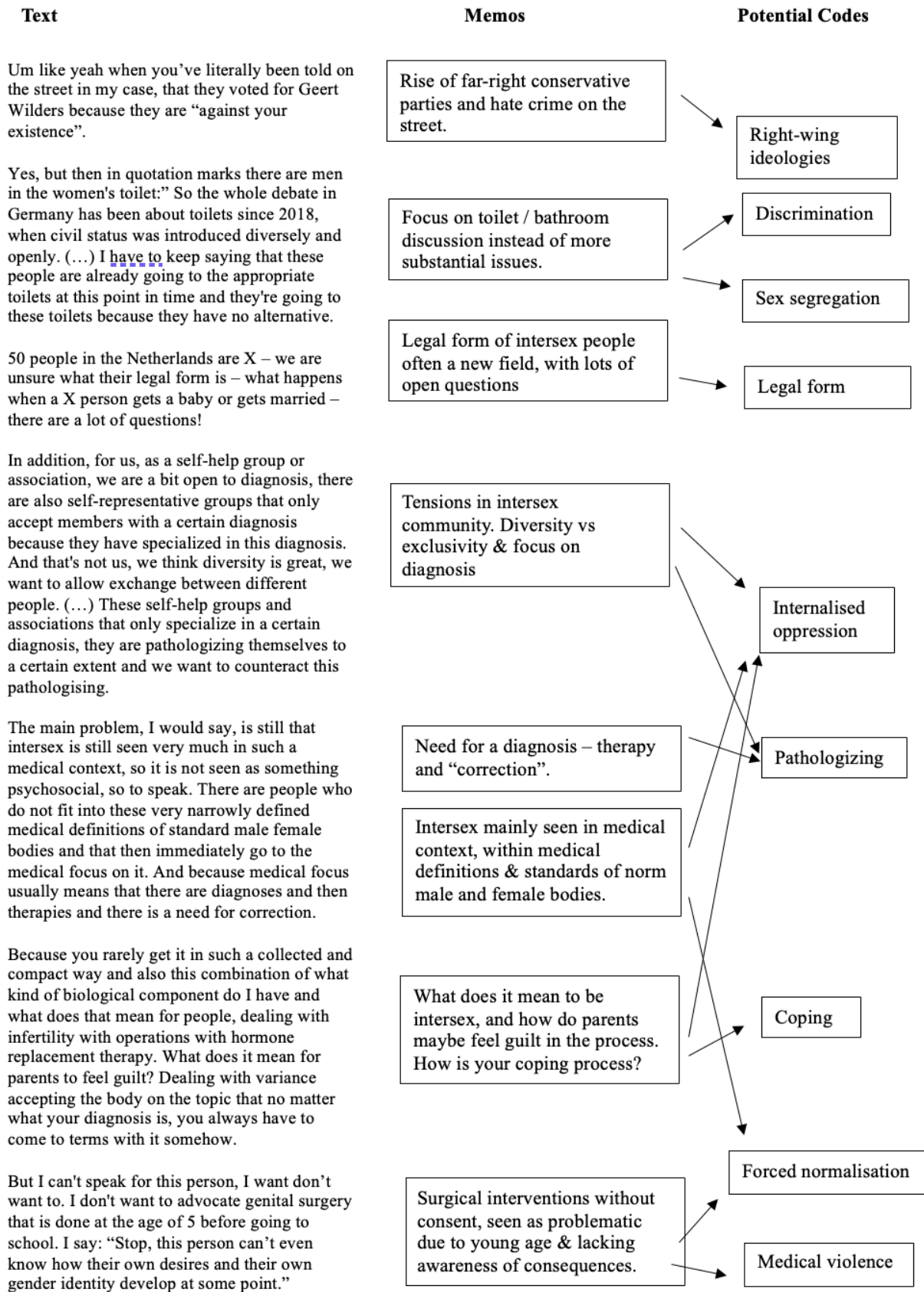


Figure 3 From text to code (inductive), own design (Hennink et al., 2020, p. 331)

### 3.3.2 Critical Discourse Analysis

#### Search criteria and analysis

The selected documents, brochures and flyers were chosen based on different search criteria including geographical, temporal, and topical relevance (Locke, 2004). Similar to the interviews, the documents represent a range of perspectives within the intersex rights movement, including medical, legal, and personal viewpoints. It is to be noted that a few of the represented texts are funded by impactful organisations in intersex advocacy. Including these sources was a central aspect of ensuring their representation in the work, as they haven't been represented in the interviews. All documents and authors are listed in **Fehler! Verweisquelle konnte nicht gefunden werden.**

In total 10 documents, brochures, statements, and flyers were analysed. After the selection of the data, contextual factors were questioned e.g. why it was published around a specific time, or the context of the production. After a first scan, the first pages were read to determine the purpose of the text, what the main topics were and which visibility/framing wanted to be achieved e.g. human rights lens, or medical lens. Afterwards, the rest of the document was read multiple times and more detailed topical points were worked out, which were partly determined by the interview findings, and theories (Locke, 2004). A more detailed protocol of the analysis can be found in Appendix E.

### 3.4 Positionality

Coming from Germany, a predominantly white, middle-class environment, I recognised that my cultural context might limit my understanding of intersex issues in more diverse or less privileged settings. Furthermore, as a member of the LGBTQIA+ community, my own experiences with discrimination introduced potential emotional biases, particularly on topics related to discrimination. Additionally, my personal experiences as a woman who does not conform to traditional female norms influenced my understanding of gender-related issues. These experiences helped me empathise with participants facing similar challenges but also necessitated careful reflection to avoid projecting my experiences onto theirs. Initially, I anticipated that my shared identity would facilitate trust with interviewees and improve access to their insights. However, I realised that queer issues and intersex issues are not synonymous and that there is a deeper heterogeneity in experiences and individuals. My positionality as an

ally may have had consequences which are further explored in the observations [section 5.2](#) of the findings. Further limitations are discussed in the conclusion (see [section 6](#)).

## 4. Intersex in Germany and the Netherlands

### The current state-of-art

Germany and the Netherlands are democracies located in Western Europe, known for their liberal political values and high levels of development (IDEA, 2023). In recent years, both countries have experienced right-wing conservative movements gaining traction, influencing public discourse and policy. In Germany, the Alternative für Deutschland (AfD) has become a prominent political force, while in the Netherlands, the Partij voor de Vrijheid (PVV) led by Geert Wilders has been vocal against gender diversity policies (Openly, 2023). These movements pose significant obstacles to intersex activism by promoting narratives that reject non-binary and diverse gender identities and pose resistance to policies advocating for bodily autonomy (Hechler, 2022). ILGA Europe reports “countless hateful statements this year” from the “far-right AfD”, among other things making fun of gender diversity (ILGA Europe, 2024, p.70).

In Germany, the main state organisation is a federalist system, where competencies are shared. This means all 16 states have their own organisation in financing and distribution systems. This has consequences on medical care, guidelines, and the financing and availability of self-help groups (Blümel et al., 2020).

As far as healthcare systems are concerned, both Germany and the Netherlands possess sophisticated, decentralised healthcare systems characterised by a neo-liberal model of insurance and healthcare provision (Blümel et al., 2020; Kroneman et al. 2016). Despite their progressive reputations, recent socio-political shifts have presented new challenges, particularly for marginalised communities (Zeeman et al., 2019). The decentralised healthcare system of both countries ensures that most citizens have access to healthcare, but it also presents unique challenges for intersex people (Blümel et al., 2020; Kroneman et al. 2016; Zeeman et al., 2019). Both systems allow medical interventions on intersex infants which often happen without consent and have been standard practice, reflecting an approach that prioritises binary gender norms. A study in the Netherlands revealed that non-consensual surgeries on intersex children are still occurring. In total 8461 surgical interventions - most of them

medically non-necessary - took place between 2014 and 2020 (ILGA Europe, 2024; ILGA Europe, 2023).

The push for bodily autonomy and the right to self-determination for intersex individuals challenges these practices (LSVD, 2021). Current developments show that the UN Committee on the Rights of the Child urged both the Netherlands and Germany to implement legislation to safeguard intersex children. The laws are intended to prohibit non-emergency and non-essential medical interventions on children with variants of gender development (ILGA Europe, 2023). While in Germany such a law was passed in 2021 (LSVD, 2021), the reaction of the Dutch Ministries was to explore the pros and cons of a ban on these non-consensual treatments on intersex children (ILGA Europe, 2024).

Touching upon other central legal advancements, in Germany civil society advocated for new legislation on legal gender recognition. In June 2023, a draft was introduced focusing primarily on self-determination and addressing issues related to intersex, trans, and non-binary parenthood. The draft also proposed financial compensation for trans and intersex individuals harmed by previous laws (ILGA Europe, 2023). In early 2024, the German parliament passed the law, while a similar draft was rejected by the parliament in the Netherlands (bundesregierung.de, 2024; Die Tagespost, 2024).

Further data shows that in Germany there is a focus on the need for “procedural safeguards” and “accountability mechanisms” for medical practitioners (ILGA Europe, 2023, p. 67). In the Netherlands, the Dutch Professional Association for Psychiatrists issued an apology for the harm caused to LGBTQIA+ clients by attempting to “cure” them, as they were previously regarded as “disordered” (ILGA Europe, 2024, p. 111). Furthermore, intersex and trans individuals in the Netherlands received compensation for medical interventions under the “transgender law” between 1985 and 2014, which had consequences on their fertility and bodily integrity (ILGA Europe, 2023, p. 105).

The COVID-19 pandemic has further complicated the socio-political landscape. In Germany e.g. the halt of COVID-19 relief funds has strained the social sector, affecting support services for marginalised groups, including intersex individuals. This financial strain has made it more difficult for advocacy organisations to operate and push for necessary reforms (Interview 9, own source).

Generally, there has been a stagnation of the positive perception of the LGBTQIA+ community in public opinion, as well as a rise in bias-motivated violence, showing an increase in sexual harassment, physical assault, and vandalism (ILGA Europe, 2023). Based on this knowledge,

German civil society groups criticised the Democracy Promotion Act for its vague provisions on future funding, its inadequate intersectional perspective, and its neglect of hate crimes targeting LGBTQIA+ individuals (ILGA Europe, 2023).

Interestingly, when looking at German and Dutch efforts in other countries, it can be highlighted that both Dutch and German-based donor organisations play a notable role in promoting LGBTQIA+ rights abroad. These organisations often support initiatives that advocate for the rights of sexual and gender minorities in developing countries. However, this international advocacy can sometimes contrast with the domestic challenges faced by intersex people in these donor countries, highlighting a disconnect between external and internal policies (Holzhacker, 2007; Holzhacker, 2012).

A comparative analysis reveals that while intersex issues in regions like Latin America, Africa, and Asia are often framed around "cultural beliefs" similar cultural dynamics are present within Europe (Mestre, 2022, p.10). The decolonial lens shows that these issues are also racialised in Europe, with cultural differences influencing the development discourse. Simplistic narratives that blame cultural beliefs for intersex discrimination in developing countries ignore the complex, racialised nature of these issues in developed nations as well (Rubin, 2017).

## 5. Results

In the following, the findings of the two methods are discussed. Firstly, the insight of the in-depth interviews will be laid out. Secondly, a discussion of the current advocacy campaigns and their strategies will follow. Both chapters will reflect on the role of agency.

### 5.1 Struggles and experiences of intersex people

In examining the struggles and experiences of intersex people, a distinction can be made between societal and emotional struggles. Societal struggles are defined by societal influences on the intersex community, such as social dynamics, medical practices, and legal frameworks. Emotional struggles refer to the inner complexities of intersex individuals, the experiences of parents and within the community itself. It is important to note the interconnectedness of many experiences, making a distinction between different sectors, norms, or societal and emotional struggles difficult. However, for this analysis, an attempt will be made to differentiate these aspects in the following findings.

#### 5.1.1 Emotional Struggles

Impacts of secrecy and internalised oppression

*“For me, that was the hardest part (...). That you’re a kind of freak, that there is no one like you. When people will know who you really are, they will run away, they will hunt you somehow. And that’s the part where I get most angry about too because I was learnt from a very small age through my parents, but it was actually a message from the hospital that: You can’t tell anyone, you cannot share or people will bully you.(...) And then at some point, it was actually after therapy, I was 21 or 22. And I had to learn to see that in the last 20 years, I started to see myself as this monster.” - Interview 14*

M. shares these experiences when talking about the impacts of being told to keep secret about being intersex, building up shame, and feeling like a “freak” for being considered different from the medical standard. For M., this results in a fear of rejection and isolation if the intersex status is “revealed”. For many intersex people, these fears are being reinforced from a young age, by parents or medical instances, indicative of the societal norms that pathologise intersex bodies and expectations regarding gender and bodily appearance. The psychological impacts

of this secrecy and expectations are profound and shown by the quote's need for deconstructing internalised narratives. Agency, in this context, is reclaimed by therapy and self-reflection as key components. Coming to terms with this can take big parts of the lives of intersex individuals - which could explain why some are not engaged in activism. L. explains a similar decision L. had to take, touching upon coping mechanisms and self-determination.

*"I'm no longer a victim, I'm acting, and I don't want to be a victim anymore. This is the gain we have when we go into activism."* - Interview 6

This quote shows the choice intersex individuals can make, and gain joy from deciding to not be a victim of oppression and medicalisation anymore. While this is one path, other interviewees brought up the aspects of internalised oppression, showing in questions like: "Why doesn't my period come? I am a woman." Often combined with expectations of a "normal family" with a husband, and many kids - then being confronted with the question of infertility. Further displayed in this interview:

*"We have people coming here, who just think something is different in my body and why isn't my period coming now? (...) Because their first tendency is usually: "Yes, but what can you do now? Because I'm a woman or I'm a girl". So, I think there's just an incredible amount of inexperience and questions. People first have to be guided and first of all learn what's behind it to be able to even think: OK, what does this mean for me? As a result, maybe that means that they say: "I don't want to get into this binary system at all", but that's a big swing. I don't just simply doesn't tell a fifteen-year-old girl that up until then was waiting for her dream prince and dreams of a big family - Yes, then a world is collapsing."* - Interview 8

This data shows that these societal structures can lead to vulnerable feelings of inadequacy or uncertainty about one's place in society, particularly if a person does not fit traditional gender roles or expectations. This is also often very dependent on the values that were communicated during childhood, and the environments a person moves in.

## Parents and family

*“We are really simply fighting to get parents out of this idea that you could change the underlying variants through surgery. They are then very upset because there is this perception of: “Oh, you can operate on that. That's what we're doing now.” And we have to intervene and say: ‘No, we’re not just going to do that.’ - Interview 8*

This quote illustrates further what has been touched upon above. Family members of intersex people can be one of the first institutions that question their existence before medical staff. The quote shows some parent’s perception of the necessity of surgical interventions for intersex children. The interviewee addresses the misconception that surgeries can "change the underlying variants," showing the existing beliefs of parents that intersex variations are medical conditions to be corrected rather than accepting natural human diversity. The interviewees stated that this belief is deeply rooted in a medicalised view of intersex bodies, where non-normative physical characteristics are seen as needing fixing. This can stem from expectations and societal pressures to conform to binary gender norms and the fear of their child facing stigma or discrimination. Parents may feel a sense of parental guilt, failure, or fear about their child’s future, driving their initial wish towards surgical intervention, which is further shown in this quote:

*“And they have to face the very hard question, who do I tell? So it’s a swaddled baby, a babysitter will be coming soon. I meant: keep it pragmatic: ‘Please clean this and that. That's just what it looks like and there may be one more crack than usual.’ (...) Or ‘I have a clinic appointment, what should I say then?’ (...) I'll say in a region where there is a solid AfD election, and I can't completely dismiss this.” - Interview 11*

It also shows the far-reaching impacts of the political landscape on the lives of people. The mentioned pressure continues throughout the child's life. It was highlighted that parents need to understand that they no matter if surgery or not should support their child emotionally, physically, and socially. Based on the data, the participants often question parental authority, and whether parents have the right to decide what is best for their child's life. Some interviewees emphasised the importance of self-help and education within the family, challenging the conventional idea of the family, as an institution for control of gender and sexuality, and promoting a support system that embraces diversity and individuality.



## Self-Pathologisation and gatekeeping

*“There are also self-advocacies that only accept members with a specific diagnosis because they have specialised in this diagnosis. (...) That's where I would say: Yes, they are pathologising themselves to a certain extent, and we want to counteract this pathologisation.”*

- Interview 5

A struggle described by an interviewee is the differentiation within the intersex community based on specific diagnoses, which can lead to self-pathologisation - reinforcing a medical narrative for themselves. Some groups focus exclusively on particular diagnoses, while others aim to celebrate the diversity within the community. This tension can further be detected in the different approaches to representation and visibility within the intersex community. Some individuals want to emphasise the sorrow and pain associated with being intersex, adopting a victim role to highlight the struggles they face. In contrast, others focus on joy and hope, rejecting the notion of being patients and instead embracing their intersex identity with pride. M. explains it by using language as a tool: "Ik ben interseks." (I am intersex) instead of "Ik heb interseks." (I have intersex), refusing the framing of "having a disorder", but proudly "being" intersex. This can be observed not only in the context of self-pathologising but in intersex groups, as something called "gatekeeping", illustrated in this quote:

*“Gatekeeping simply means that when it comes to intersex, for example, there is a list in medicine that is very limited to certain variants. And sometimes there's a bit of resonance in the intersex community that says: ‘Ah, variant XY counts as being intersex but everything else doesn't.’ But it isn't like that, the label ‘inter’ was created by the community in the first place and was also reclaimed to empower us and promote more visibility. And it always resonates a bit that diagnoses are then played out against each other within the community or people are simply afraid to go to certain spaces because they think: ‘But maybe I don't belong here, maybe I'm not intersex enough.’”* - Interview 2

A notable issue is the gatekeeping and validation of intersex identities within intersex groups, which often leads individuals to question their belonging and worthiness of being “intersex enough”. Within the various realities of intersex individuals, managing diversity often involves navigating the politics of differences among differences, where the question gets raised of which differences are considered to matter more than other differences (Gunew, 1994). A

similar dynamic can be detected in connection to the LGBTQIA+ community, discussed in [section 5.1.2](#).

## 5.1.2 Societal Struggles

### Medical

The primary framing in which intersex topics are discussed often centres in the medical field on diagnosis and the perceived need for therapies and corrective measures, leading to the pathologisation of intersex bodies. This focus perpetuates the idea that intersex variations are medical conditions that require fixing or correction. In this context, intersex is often talked about as “disorder of sex development” (DSD) and intersex people are referred to as patients, classifying them and their bodies, mostly against their perception, as medical emergencies.

### **Surgical interventions and consequences**

*“What always comes to mind is the operations have to stop, so that's something so frustrating to see that despite all the positive changes, despite all the protective measures at the legal level at the level of the medical societies and so on to see that the numbers just don't go down. (...) There are some indications that this law does not offer the scope of protection that it should.”*

- Interview 10

Despite the existence of surgical bans, surgical invasive procedures continue at significant rates, with little to no decrease in numbers. This persistence highlights ongoing issues in the effectiveness of the law highlighted in the quote. Critical voices argue that this law mainly protects children who fall directly within the medical definition of intersex, while others closer to the margins remain more vulnerable. When there is the question of surgery, the decision is regulated by a multidisciplinary commission consisting of professionals from various fields. This commission advises the parents, but a judge makes the final decision based on the given recommendation.

*“The surgical ban from 2021 has completely changed a legal norm in Germany. This is not enough, it was a good start, but it doesn't include all children, but rather gives the medicine the power to sort again: who is now intersex, who is DSD, who is differentiated enough to undergo surgery under this protective framework against referring genital changes that are*

*not medically necessary. I demand a ban on operations on the genitals of all children.” - Interview 6*

The question of the effectiveness of the law also raises the concern of values, on which decisions are made. Within the judicial and medical context, a lot of power is distributed between doctors and judges, who can make the final decisions to proceed or stop surgeries. The power distribution reflects where state and medical authorities exert control over bodies to enforce normative standards. In practice, this power can lead to continued pathologisation, inconsistent legal protection, or a decrease of trust in efforts between intersex individuals and the medical community.

*“We had the topic of ‘surgery regret’ (...) And well, people are coming to terms with what was decided and I think they can also grow up with the confidence that their genitals look different and that that's okay. If they experience this in the family, then that's okay. And on the other hand, I know from our consultation hours, I think of a person who is already an adult and says clearly: Looking back, I wish they hadn't had done the operation.” - Interview 11*

The interviewees speak of far-reaching effects, impacting both physical health and emotional well-being. While the consequences of surgeries are discussed within intersex advocacy circles, there is often too little awareness among the broader society, including parents. Peer consultations highlight the need for greater awareness of potential outcomes to enable agency for intersex individuals. While there can be feelings of “surgery regret”, where the long-term consequences of these interventions become apparent, others cope with the decision that has been made.

### **Forced normalisation**

*“And also gender norms - a boy who has to be able to pee standing up - that's often the topic, no joke. And norms, I would say that breaking down norms is always an issue when working with variants of gender development.” - Interview 11*

The objective of forced normalisation is to conform intersex bodies to medical and societal norms. An interviewee from the medical sector specifies that these norms often involve tightly defined criteria for what constitutes a “normal” body. This includes differences in chromosomes or the look of genitalia e.g. the length of the urethra and where the urethral

opening is. When a child is considered biologically more male, but there are indicators like the opening of the urethra being closer to the back than in the front of the penis, medically it is considered a “reduced masculinisation”. This can be a deciding factor in the decision for or against a surgery. This drive to normalise or fix intersex bodies degrades their natural variations, imposing harmful standards that do not account for the diversity of human biology and recreate gender norms.

### **Medical violence and Quality of care**

*“In medicine, I always notice privately that there is a lot of ignorance and that people who are intersex don't get the hormone therapy that would be good for them. But that's how it works out it's purely based on the gender that was assigned at birth and that is then assumed.” - Interview 2*

A major point of criticism within the medical field is the lack of quality in care and the diagnostic process. An intersex interviewee shows up what is missing:

*“What I also wish for is that this will be the norm, coming into the treatment room and then simply being asked: ‘What kind of treatment do you want? Or what is good for your body? What kind of experiences have you had?’ And not that what is supposedly good for us is simply decided over our heads.” - Interview 2*

The treatment context often utilises a reductionist approach, where the focus is mainly on the appearance of their genitalia and the categorisation into syndromes. This fixation is connected to administrative processes and the assignment of gender, which can overshadow the individual's identity and personal experiences. This is closely tied to a significant lack of validation for intersex individuals' knowledge of their bodies and their gender perceptions. Treatment decisions, such as hormonal interventions, are then made externally without any consideration of the person's perspective. This approach fails to acknowledge that bodies are unique.

Experiencing daily discrimination and often not being taken seriously or not recognised in their identity, in not conforming to binary gender categories, can lead to suicidal thoughts, or not seeking medical care. An interviewee clarifies that boundary-overstepping treatment can be life-threatening, and an example of inclusive measures.

*“For example, as a person who coordinates a consultation hour, how can I deal with the fact that I call people by their first and last name instead of Ms. or Mr. And that's really good and free and we need something like that more and systematically in training courses. Because it also saves lives, to put it briefly.” - Interview 11*

## Legal & Policy

### **Legal discrimination & Outdated laws**

The interviewees show that the legal recognition of individuals outside the male and female binary in Germany is a recent development. This resonates in that many legal frameworks, including anti-discrimination laws, are often formulated in a binary manner, such as promoting "equal opportunities for women and men". This binary structure can lead to legal discrimination against intersex individuals. An example given by an interviewee is one in which an employer may be sued if they deny customer interaction based on an employee's gender. While legal categories mostly struggle to incorporate all human differences, there is significant potential to revise these frameworks to better accommodate and respect the diversity of human gender identities. This would also have an impact on other aspects like compensation:

*“According to a report by a UN panel of experts, these genital operations at German university hospitals are a violation of CAT, i.e. the “Convention Against Torture”. In 2010 we were proven right. All 8 cases have been recognised as cases of inhumane treatment within the meaning of the UN Convention on the Rights of Torture. The sad thing is that to date not one case has been compensated.” - Interview 6*

Despite the recognition of the trauma and harm caused by non-consensual medical interventions, intersex individuals often face significant barriers to obtaining compensation. While there are instances where lawsuits are filed for the removal of functioning gonads, compensation payments are unusual, even when being recognised as a victim of torture. The lack of compensation reflects broader issues within the legal system that fail to address the injustices faced by intersex individuals.

### **Rise of far-right**

*“The discourse surrounding gender is becoming extremely polarised at the moment. Unfortunately, this has just become a bit of a scapegoat because of right-wing positioning. (...)*

*And also the topic of gender, the negative emotions are really being created and that's the problem always that this also affects intersex people.” - Interview 4*

The increase in conservative opinions in public discourse, as well as discrimination, has led to a heightened "fear of being out" reduced media presence, and greater invisibility for intersex individuals. Interviewees warn that the topic of intersex rights is often instrumentalised by conservative groups to maintain the status quo. This works by leveraging fear to support their agendas, spreading misinformation, and creating a climate of censorship around the use of gender-neutral language. They argue that traditional language is being banned which feeds fears about the collapsing of societal norms.

In their opposition to gender diversity, conservatives often dismiss the existence of intersex individuals. With “normal”, right-wing voices mean heteronormativity and related sexual desires, and the supposedly natural order of man and woman who are the basis of reproduction (Habarth, 2008). They fire up fears about the destruction of the traditional family structure, reinforcing outdated gender roles.

### **Issue of refugees and migrants**

*“And when it comes to culture, we have several patients from Arabic cultures. And that's where this taboo kicks in, so incredibly much. I think that it is sometimes a reason to flee and yes, this turns the entire family inside out.” - Interview 11*

The deep-reaching impacts of being intersex or having an intersex child are clear when the topic of migration is brought up. Significant gaps are revealed in the current framework that recognises reasons for seeking asylum. L. specifies that while some LGBTQIA+ reasons are acknowledged, intersex reasons to flee are further overlooked. By linking it to a development perspective L. further highlights a critical intersection of cultural practices, human rights, and migration. Furthermore, the need to expand human rights frameworks to include intersex individuals and migration policies to reflect on the complex realities faced by cultural pressure. Additionally, culture was spoken about in the context of caregiving. An example was proposed by an interviewee that when people from different countries work in caregiving roles, they bring their cultural values and perspectives. This can significantly influence how they interact with and treat intersex individuals. The interviewee mentioned this with a hint of concern, to which values are then going to be more important, and that despite cultural differences, it is essential to foster an environment that respects and affirms their identities.

## Social struggles & connection to other groups

*“As soon as a child with a diagnosis of variant gender development enters the room, the topic of gender norms is there: ‘(...) He is a boy and he loves playing with excavators and the child was a boy from the start’” - Interview 11*

The discussion on societal issues is shaped by gender norms, as displayed in the quote. Other topics are the binary system and heteronormativity, as they dominate the main discourse of intersex topics, displayed in the following section.

### **Sex segregation**

*“Yes, but then in quotation marks there are men in the women's toilet” So the whole debate in Germany has been about toilets since 2018 when the civil status diverse was introduced. This is a situation that I don't understand, so I'm starting to lack patience in debates like this because I have to keep saying that these people are already going to the appropriate toilets at this point in time and they're going to these toilets because they have no alternative.” - Interview 5*

This concern reflects on the misunderstanding of sex segregation, building upon hypothetical fears rather than lived realities. The frustration of the interviewee stems from needing to justify a matter of basic rights and dignity, such as using a toilet, and the discussion being defined by a lack of alternatives for impacted persons. The broader implications of this debate touch upon the challenges of acceptance and accommodation for intersex individuals within public spaces which are structured around the binary gender system. Other impacted social sectors with similar discussions are the military, or sports where intersex athletes are banned from sports events.

### **Lack of representation**

*“The idea is not just a medical construct but when people hear about this topic for the first time, it is blatantly exoticised. Then they have very exotic ideas: how bad these people must look and they can't even imagine it. And then you can see on the posters that they just look like your neighbours.” - Interview 10*

Intersex individuals frequently confront stereotypes that paint them as exotic or abnormal, leading to frequent discrimination. Interviewees mention misgendering or constant questions about the looks of their genitalia, asking for greater awareness and sensitivity in societal interactions. To tackle these stereotypes, interviewees mark the lack of representation in political bodies, the cultural sector, or sports. Without representation, the unique needs and perspectives of intersex individuals are often overlooked e.g. in policy-making processes. Further, there is a strong call for introducing education about intersex variations from an early age, starting in kindergarten and continuing through elementary school. Integrating accurate information about intersex into curricula and promoting diverse representations in educational materials can help challenge the male and female binary.

### **Relationship with the queer community**

The relationship of the queer community and the intersex community is seen as complex. Generally, it is recognised among the interviewees that the queer community has fostered greater acceptance and inclusivity for intersex individuals. While the intersex and queer communities share common ground on issues such as discrimination and challenging normative structures and the gender binary system, tensions exist as well. Not all intersex individuals identify with the queer community or feel the desire to contest societal norms but are rather living within them. They argue that LGBTQIA+ topics are not the foremost concern when dealing with the significant impact of an intersex diagnosis on their lives. Further, the queer community is often criticised for not adequately addressing intersex issues, highlighting the ongoing politics of difference. Furthermore, a close association can lead to the erasure of intersex-specific concerns.



## 5.2 How do they strategise and campaign to change society?

In the following analysis of interviews, and the critical reading findings, the focus shifts from struggles and experiences to how advocacy efforts highlight these. This section examines how advocacy campaigns make intersex challenges visible, enhance agency and facilitate access to developmental services. The diversity campaigning needs to touch upon is shown in this quote with the former political queer spokesperson of the green party, B.:

*“Questions were asked: What do you do in more rural parts of Germany? Then you also have to give workshops to children and youth workers to educate them and spread knowledge. (..)Also which educational material do I use - which topical focus do I set? Are there books that show pupils’ gender diversity? And how do we finance it?” - Interview 9*

The diverse range of advocacy campaigns, which gained momentum over the last years, is often a multifaceted combination of different approaches within an activist group, reaching from direct action to policy dialogues, and focus to general reach campaigning. In the following, the campaigns are further discussed.

### 5.2.1 Target groups, strategies, and framing

A recurring theme in the interviews is the question of responsibility. In the medical sector, the responsibility is seen mainly with the health ministry to create binding guidelines and policies. When talking about societal struggles and discrimination, the responsibility is considered to lie with everyone in recognising gender diversity. The location of responsibility gives information on the target groups and goals of advocacy campaigns. This is illustrated in the quote of L. when asking about L.’s activist focus:

*“In recent years I have focused a lot on legal things because I believe it is a very sharp sword and law covers a broader field than medicine.” - Interview 6*

The connection between the medical and legal sectors is complex. While some interviewees believe that laws are the beginning of change, others see laws only as a codifying behaviour that is already accepted and want to relocate the focus to targeting medical professionals.

Generally, different approaches to advocacy are shaped by whether strategies are collaborative or confrontational (Davis, 2015). The mainly implicated collaborative strategies involve working with institutions to effect change, while the less used confrontational strategies challenge and resist existing power structures. Especially in the medical sector, the biggest tension between these strategies can be detected. An interviewee from a specialised centre for intersex individuals specifies:

*“Yes, so there is an exchange with intersex organisations. You have to say that it has grown over many years and it had to grow. And it wasn't always easy at the beginning because there were fears of contact on both sides, of course, you will also know that there are activist groups for which everything that has anything to do with medicine is called: Nazi medicine and mutilators. And those would not be willing to enter the discussion.”* - Interview 8

While some organisations don't want to cooperate with the medical sector at all calling them in general “mutilators”. Others base their efforts on collaborative grounds to achieve improvements. Activist L. specifies:

*“We also always try to engage with the medical networks. This contact is part of our strategy not to cut off these lines completely, but to always try to stay there in the system in order to reach those who are important to us.”* - Interview 6

Hence, this raises the question - as medicine is normally seen as the main domain of intersex struggles – why there are more efforts directed towards the legal domain? Findings show that the medical sector is often only targeted with educational and collaborative efforts, possibly aiming for medical self-reform described in the theoretical part by Bauer et al. (2019, p.1). Interviewees mostly mentioned working together with politicians, or medical experts, aiming for introducing new terms, and political or legal negotiation. Further goals are building a network or sharing information and knowledge.

### Insights of the Critical Discourse Analysis

The critical discourse analysis gives more insights into the framing used by advocacy efforts as well as the language used, which has ultimately influenced on discourse and reality surrounding intersex topics.

The primary framing used in the documents is a human rights approach, emphasising several key aspects. This includes a strong focus on discrimination and the heightened vulnerability of intersex individuals, which underscores the urgency of addressing these issues. The documents are evidence-based, incorporating documented experiences, personal accounts, and shadow reports to substantiate their claims (OII Europe, 2021). Major themes include dignity and recognition, social acceptance and visibility, promotion of self-determination, and legal protections. Additionally, there is a significant emphasis on visibility and destigmatisation, along with a critical view of the medicalisation of intersex bodies. Looking at the rhetoric used, in a statement by OII Europe on the “Victim’s Right Directive” intersex individuals are immediately put as a high-risk group for gender-based and domestic violence, setting urgency and concern to this topic. Terms like “non-vital intervention” (p.7), “without the person’s own wish”(p.8) emphasise the non-consensual nature of IGM. The inclusion of extreme examples, such as rape by medical doctors, underscores the severity of the violations faced by intersex individuals (p.3) (OII Europe, 2021).

The second framing detected is based on awareness, visibility, and knowledge as empowerment. The texts are mainly narratives navigated by intersex voices and perspectives. The texts foreground the voices of intersex individuals, highlighting their agency in recounting their experiences and advocating for their rights. Visibility is framed as a tool to demand societal change. The authors call for a shift in how society and the medical community view and treat intersex bodies, pushing for acceptance and informed consent. The framing avoids medical terms, focusing instead on personal experiences and social implications. There is often no mention of any positive outcomes of experiences, which may exist but are not included to avoid undermining the overall critical perspective (Kromminga & Ghattas, 2019). This approach emphasises the human cost of medical interventions and aims to foster empathy and understanding among the broader public.

The less used medical framing highlights a possible shift towards recognising intersex issues as social and human rights concerns (Bauer et al., 2019). A critical voice, such as the AGS parent initiative, which wasn't represented in the interviews, still views intersex issues strictly as a medical problem, classifying bodies within the gender binary (AGS, 2017). More progressive medical framing questions the values of medical staff and promotes respect and understanding while underlining the importance of peer support (TransInterQueer, 2020).

## 5.2.2 The four main campaigning efforts

Based on the categorisation of activism (see [Figure 2](#)), and the findings of the interviews, four categories were worked out to differentiate between different advocacy efforts and their impact on enhancing agency, and access to developmental services.

### Visibility and Awareness efforts

These efforts are aimed at raising awareness and visibility about intersex issues. They range from participating in pride parades and commemorating *Intersex Awareness Day* and *Intersex Day of Remembrance*. Other strategies are podium discussions, information stands, organised poster or portrait campaigns, and appearances in media like newspapers, TV, documentaries, podcasts, or art exhibitions.

These efforts are mostly direct action, which follows a confrontational strategy (Davis, 2015), creating “a first personal experience with intersex people” by confronting people on the open street, with the term who might have never heard about this before. The campaigns serve not just to educate the broader public but to make intersex identities more approachable and understood, breaking down barriers of stereotypes and prejudice by “giving them a face” (own data). By creating a counter-narrative, an alternative to the narrative of cis-heteronormativity is given to the intersex community.

Interviewees underline by providing this form of knowledge, and representation, the possibility is given to intersex individuals to reclaim and lead their discourse. Further, giving them direct control over how their narratives are shared and issues are presented, challenging the erasure as a marginalised group.

### Observations

Fitting with these findings are possible unintended consequences of increased visibility. Interviewees explain it as a silver lining between representation and being on display. The social climate further complicates advocacy, with hate comments on social media posing a threat to emotional well-being and privacy. Moreover, capacity plays a crucial role, as advocacy efforts require emotional energy, temporal, and monetary resources, leading to potential burnout.

The observations support these perceived dynamics. Due to the sensitivity of the topic, the positionality of the researchers was questioned on the purpose of the research. Hence, there was and is a high awareness of the risk of becoming part of a ‘political project’ that isn’t one

of the intersex community with the consequence of not being able to navigate the narrative. Further, they need to defend themselves from dominant and upcoming discourses around the body, sex, and sexuality to prevent being made invisible. This makes it more clear how complex the concept of agency is, underlining that the act of compliance within power structures can be seen as agency as well.

### Community Support and Empowerment

*“Yeah. I went to the peer group when I was 11 and it helped me a lot. I think it is the reason why I survived puberty because I felt alone. But I knew there was this group that I saw 3 times a year where I could feel completely liberated and free and express everything.”* - Interview 14

This quote highlights the importance of self-help as a valuable source for creating safer spaces for intersex individuals to share their experiences and receive guidance. This can help them free themselves from above-discussed internalised oppression, fostering a sense of agency (Crocetti et al., 2020b). Under these efforts fall (peer-)counselling and organised community meetings. These efforts are mainly organised by self-advocacy organisations that offer intersex individuals and their families a platform for mutual support, and offer an alternative to the narratives of secrecy and shame, represented in the following quote:

*“I got to activism because of a realisation, as I was informed very late, that I had a gonadectomy without my free, informed consent - that made me resistant. I used to see this as an individual fate, which could have been prevented. And it was only through contact with self-help, that I realised that the whole thing was structurally based, that it represented structural violence.”* – Interview 6

The focus on structural violence connects to the topic of changing society, as intersex individuals as marginalised groups create their own spaces and narratives to counteract current oppressive structures. Close to these efforts are also community and leisure activities, which go beyond the more formalised efforts, but play a vital role in normalising intersex identities within society. These events strengthen community bonds and emphasise that intersex individuals partake in societal activities (e.g. a book club), additionally challenging the notion of otherness. As shown in this quote:

*“Yes, I always find it amazing at meetings that there are very openly queer people exchanging ideas with people who live married in a single-family house in the village and lead a very ordinary life and yet they still have something in common topic of conversation. I think that's super fascinating.” - Interview 5*

Touching upon the access to developmental services these meetings are central for networking and referrals, connecting intersex individuals with specialised services and support groups.

### Legislative and Policy Efforts

These efforts mainly focus on influencing policy and legislation. Efforts around the Self-Determination Act (*Selbstbestimmungsgesetz*) in Germany exemplify this, seeking to replace outdated laws, their outdated terms and language, and facilitate easier legal recognition for intersex and trans individuals. These campaigns underscore the role of legal frameworks in affirming the rights, dignity, and bodily autonomy of intersex people, advocating for crucial changes like the prohibition of non-consensual medical interventions on intersex children. These efforts primarily involve collaboration with politicians and legal institutions, targeting indirect rather than immediate impacts. This process can be long, often requiring efforts to identify supportive politicians and engage in lobbying activities. Unlike scenarios where politicians proactively engage with self-advocacy groups, these efforts often necessitate proactive outreach and advocacy from the groups themselves.

This is further specified in efforts from intersex people themselves to revise legislative proposals that affect the intersex community. Additionally, engaging in panel discussions and public forums to discuss the impacts of new laws and legislative changes on intersex individuals, provides a platform to voice concerns and push for beneficial legal frameworks. Legal recognition is crucial for intersex individuals to access various services and rights, including healthcare, education, and employment, without facing bureaucratic hurdles.

### Educational Efforts and Knowledge

The educational efforts are directed at different target groups, such as universities, schools, social workers, administrative staff, midwives, kindergartners, allies, or medical staff, depending on the target group the topics of workshops, or training change. An interviewee who gives workshops, explains that this can range from explaining the basis of what intersex is (e.g.

case studies), to administrative knowledge on gender entries and civil status law. This underlines the need for systematic efforts in many sectors of society.

The educational efforts include the development and distribution of educational materials, the development of quality measures or guidelines, and the conducting of workshops. Working on these efforts together with intersex individuals ensures respectful practices based on the knowledge of intersex people themselves. These initiatives aim to highlight autonomy, inform best practices, and advocate for the respect and rights of intersex individuals.

However, this education should also be directed at intersex individuals themselves. An intersex interviewee recognises knowledge as one of the most powerful tools for agency. Providing intersex people with knowledge of their bodies and situations provides them with a crucial tool in combating feelings of secrecy. The interviewees underline that this allows individuals to challenge misconceptions, and with more knowledge on rights and available services make informed decisions easier.

## 6. Discussion and Conclusion

This research aimed to explore the struggles and experiences of intersex individuals in Germany and the Netherlands. This included examining how advocacy campaigns enhance agency and voice, and their impact on facilitating access to developmental services. Thus, contributing to a deeper understanding of the intersection between intersex issues, gender and decoloniality.

Circling back to the stated problem statement, intersex struggles are still not highlighted and worked on enough to offer sufficient protection and basic human rights to intersex individuals. To this day there is the continuous execution of medical interventions, despite new laws that try to prohibit these. Furthermore, intersex individuals face daily discrimination, and recently gained the role of a scapegoat for far-right opinions, as shown in the results [section 5.1](#). In this work, the findings highlight these struggles and experiences, while gaining knowledge on how to move forward through activism and advocacy.

The work researches the given objectives in the Western contexts of Germany and the Netherlands, examining how the existing power structures intersect with decolonial theory. Through the adaption of a decolonial lens, taking inspiration from Ndlovu-Gasheni (2012), who identifies the “control of gender and sexuality” as one of the four colonial matrices of power (2012, p.49), the study reveals critical insights into present colonial structures, their ongoing impacts on marginalised groups like intersex individuals and how to change these. Therefore, questions of binary norms, heteronormativity and how to better the living quality, medical care and legal protection of intersex individuals were posed in the conduction of this work. This chapter aims to connect the insights which have been gained so far and to place the stories of intersex individuals in the broader societal and literary context.

Hence, answering the main research question, which was posed in the introduction: “*What are the struggles and experiences of intersex people in Germany and the Netherlands, and how do they strategise and campaign to change society?*” The given four sub-questions were already discussed in [sections 5.1](#) and [5.2](#).

### Experiences and struggles of intersex people

To summarise the major findings, firstly the struggles of intersex individuals can be categorised into emotional and societal categories. Societal struggles often involve the lack of legal recognition, which in turn affects their access to basic services, such as healthcare, problems with sex segregation leading to exclusion, and ongoing non-consensual medical interventions



(see section 5.1.2). In contrast, emotional struggles encompass feelings of guilt, oppression, dynamics within the community, and coping mechanisms. These emotional aspects are crucial, as they impact the overall well-being and sense of agency of intersex individuals (see 5.1.1). The differentiation between these experiences highlights the variety of challenges intersex individuals face to this day. Societal struggles demand an approach of systemic change, to tackle non-consensual medical interventions or the issue of legal protection. By interviewing intersex individuals, this research received insights on various topics, discussing their importance, and necessity to work upon them. This knowledge can have major influences on dismantling oppressive systems and recognising diverse intersex realities.

Emotional struggles, on the other hand, are mostly personal and touch upon coping mechanisms, community dynamics, trauma responses or feelings of guilt. Further, reflecting on internalised oppression or psychological impacts of living within power structures that fail to accept intersex bodies. Hence, these struggles are also affected by societal attitudes and the treatment of intersex individuals, which can be impacted by colonial norms (Adamson, 2022; Ndlovu-Gatsheni, 2012).

Generally, it is a central aspect of this work to gain knowledge on these struggles to use them as a basis on how to move forward. This bottom-up approach highlights the importance of the complex understanding of how to approach advocacy and its central role in reclaiming agency (see conceptual framework [Figure 1](#)). The significance of these findings shows the potential to inform activism and drive systemic change.

### Advocacy campaigning and its impact on developmental services

The second part of the main research question will be answered in the following. Generally, the advocacy efforts can be sorted into four broader categories, which combine different strategies under one topical roof. These four categories are Educational efforts and Knowledge, Legislative and Policy efforts, Visibility and Awareness efforts, and Community Support and Empowerment efforts.

As educational efforts are being directed at various target groups, they aim to inform best practices in these sectors. These mainly collaborative efforts ensure an increase of knowledge on intersex struggles, better-informed guidelines, and more recognition of systemic power imbalances. Hence, building a basis for respectful treatment of intersex individuals in all stages of their lives. This connects to a similar finding of Bauer et al. (2019), who report more efforts towards a self-reform of the medical sector based on higher knowledge. Additionally,

providing knowledge to intersex people about their bodies, rights and available services is a central tool in enhancing agency, combating oppression, and making informed decisions. Legislative and policy efforts are mainly lobbying efforts directed at politicians and legal experts, asking for lasting systemic change in laws, going beyond immediate impact. Thus, touching upon legislative change, replacing outdated laws or terminology, which wants to create a political and legal environment, that recognises the identities of intersex individuals. Community building and empowerment efforts are from intersex individuals for the intersex community to create safer spaces and offer room to share experiences. The normalisation of intersex topics and their existence in society is another goal, as well as providing networking and referral options to intersex individuals. These findings back up Crocetti et al.'s (2020a) results on an increase in peer support and the role of patient experts as trends in advocacy. Public awareness and visibility efforts, give next to creating a counter-narrative to heteronormativity and challenging stereotypes, the opportunity for intersex individuals to share experiences. This not only gives intersex individuals a face but also allows them to reclaim control over upcoming discourses. By creating visibility normative structures are questioned, and the broader society is educated. This effort is similar to what has been categorised as “discursive politics” by Davis – sharing materials to inform the broader society (2015, p. 49).

When focusing more on strategies and framing, the Critical Discourse Analysis shows that the most frequently employed framing in advocacy campaigns is a human rights perspective, with little reliance on a solely medical viewpoint. Underscoring the perceived trend towards a mainly Human Rights Framing (Bauer et al., 2019). This human rights approach, detected in the data, emphasises legal advancements and collaborative educational initiatives between activists and the medical sector, alongside community-building efforts rather than confrontational strategies. This highlights a shift towards more integrative and less antagonistic methods of advocacy, fostering a cooperative environment for change. The campaigns are challenging norms and advocating for a more inclusive and equal society aligning with the theoretical approach of this work.

By improving access to developmental services, advocacy efforts empower intersex individuals with education and resources, enabling self-determination and agency. This can be seen as a part of the exercise of providing intersex individuals with basic human rights. Through these actions, advocacy campaigns disrupt traditional power dynamics, and create a more equal society, thereby changing societal structures and norms.

## The role of agency

As displayed in the conceptual framework ([see section 2.1](#)), a decolonial approach to restoring humanity for intersex individuals is giving back or enhancing agency (Lugones, 2003 as cited in Adamson, 2022). While the findings partly indicate agency as resistance, speaking up, demonstrating or negotiating, there is also the possibility of performing agency in forms of conformity. The findings suggest that agency should not be viewed solely through the lens of defining resistance as agency, but see compliance as a not solely passive response but an active strategy that underscores the complexity of self-determination. This calls for a critical examination of what exercising agency means. By acknowledging this diversity, the research underscores the importance of also including the less visible, yet equally deliberate, choices individuals make as agency. This perspective not only enriches the comprehension of agency but also respects the different strategies people employ to navigate their social realities.

Advocacy efforts further have an impact by directly enhancing agency. The data shows a principle of "talking with, not about" intersex people emphasises the necessity of open dialogues, positioning intersex individuals not merely as subjects of discussion or within a victim role but as active architects of the norms that affect their lives ([see part 5.2.2](#)). This approach not only recognises but also amplifies the voices and experiences of intersex individuals, ensuring their participation is both meaningful and impactful to challenge normative structures.

Self-advocacy emerges as a powerful tool in this context, empowering intersex individuals to directly influence societal norms and policies that impact them. By actively participating in advocacy efforts and community events, intersex individuals gain agency, moving beyond passive roles to become key stakeholders in the discourse around intersex rights and the redistribution of power dynamics.

## Limitations and Recommendations

To further reflect on the limitations of this study, there was a bias in the selection of respondents described in the following. A point of criticism is that in-depth interviews have been held with too few intersex respondents who are not active in activism or self-advocacy groups. This could mean that the majority of intersex experiences and views shared are more politically and socially engaged, with an overall emphasis on advocacy issues, overlooking more daily discriminations, experiences and needs. This also includes the perspectives of families, partners and parents. Due to constraints of time and resources, the aspect of intersectionality could not

be further analysed and had to be left out of consideration in the theoretical thought process, and the findings. For further research, it is central to explore how intersex experiences intersect with other identities, such as disability, age, or race. Thus, providing a deeper understanding of the challenges and informing more inclusive advocacy strategies.

The following will provide a critical reflection of the results and their limitations in relation to the field of Development Studies. As seen in Germany and the Netherlands, this topic and framework have quite a potential, but critical reflection arises in the international context. Firstly, the concept of decoloniality may not be universally applicable to other countries, due to cultural, historical, and socio-political factors. What might be perceived or exercised as agency and empowerment in Germany and the Netherlands won't resonate in other countries. Consequently, risking imposing Western-centric frameworks of agency onto other contexts, paradoxically risking a new form of colonialism.

These insights inform suggestions for future research. Generally, this is a major research area, which not yet has received attention under the label of human rights in the Developmental sector. Future research could explore the transferability of these strategies and further investigate the role of agency in different cultural contexts. Opening a field for future research to explore how agency is understood and manifested in different cultural settings in the context of intersex activism. Investigating the interplay between local traditions, colonial histories, and modern advocacy efforts could provide deeper insights into the global movement for intersex rights. Another possible recommendation would be to implement a longitudinal research design instead of an explorative research design. This could provide a better understanding of the impacts of long-term advocacy efforts, providing valuable data for possible direct guidance material to inform better policies and practices.

### How to move forward?

This research aimed to explore the struggles and experiences of intersex individuals in Germany and the Netherlands, examining how advocacy campaigns enhance agency, and their impact on facilitating access to developmental services. The findings reveal ongoing struggles and a diversity of experiences, which are captured in various advocacy efforts.

When reflecting on the posed question at the beginning of the work: "Is it a boy or a girl?", the new knowledge gained reveals an even more critical intersection of societal expectations and

lived realities of intersex individuals (von Lisodonk, 2014, p.15). Beyond the current colonial dynamics of the “re-imagination of Western family” or “dehumanizing” the non-gendered – this work helps open up a space to think beyond those binaries, for people to unfold their identities while advocating for having basic human rights (Mendoza, 2016, p.18 as cited in Adamson, 2022; Ndlovu-Gatsheni, 2012, p.49). The findings underscore the importance of change to tackle binary norms, heteronormativity, and ensure legal protection and better living conditions for intersex individuals.

In conclusion, this study underscores the importance of advocacy campaigns in moving forward, highlighting both the achievements and ongoing challenges of the intersex community. By framing intersex issues within a human rights context and promoting collaborative efforts, these campaigns are playing a crucial role in decolonising societal norms and enhancing the agency of intersex individuals. This research contributes to a broader understanding of the multifaceted nature of intersex activism, paving the way for future studies to build on these findings and further the cause of intersex rights worldwide.

## References

- Adamson, A. (2022). Beyond the Coloniality of Gender. *Philosophy and Global Affairs* 2 (2):299-329.
- Bauer, M. & Truffer, D. & Crocetti, D. (2019). Intersex human rights. *The International Journal of Human Rights*. (24): 1-26. doi: 10.1080/13642987.2019.1671354
- Blümel, Miriam & Spranger, Anne & Achstetter, Katharina & Maresso, Anna & Busse, Reinhard. (2020). Germany: Health System Review. *Health systems in transition*. (22): 1-272.
- Boellstorff, T., Cabral, M., Cárdenas, M., Cotten, T., Stanley, E.A., Young, K., Aizura, A.Z.; Decolonizing Transgender: A Roundtable Discussion. *TSQ* 1 August 2014; 1 (3): 419–439. doi: <https://doi.org/10.1215/23289252-2685669>
- bundesregierung.de (17.5.2024). Bundesrat billigt Selbstbestimmungsgesetz. Selbst über das eigene Geschlecht bestimmen. Retrived from: <https://www.bundesregierung.de/breg-de/themen/tipps-fuer-verbraucher/selbstbestimmungsgesetz-2215426> [Opened on: 01.06..2024, 11.37]
- Buffington, R.M. (2007), Subjectivity, Agency, and the New Latin American History of Gender and Sexuality. *History Compass*, 5: 1640-1660. <https://doi.org/10.1111/j.1478-0542.2007.00469.x>
- Butler, J. (1990). *Gender Trouble: Feminism and the Subversion of Identity*. Routledge, New York, 33.
- Butler, J. (1997). *The Psychic Life of Power: Theories in Subjection* (Stanford, CA: Stanford University Press), 2.
- Carpenter, M. (2016). The human rights of intersex people: addressing harmful practices and rhetoric of change. *Reproductive Health Matters*, 24(47): 74–84. <https://doi.org/10.1016/j.rhm.2016.06.003>
- Carpenter, Morgan. (2018). The ‘Normalization’ of Intersex Bodies and ‘Othering’ of Intersex Identities in Australia. *Journal of Bioethical Inquiry*.(15) 10.1007/s11673-018-9855-8.
- Cislaghi, B. and Heise, L. (2020), Gender norms and social norms: differences, similarities and why they matter in prevention science. *Sociol Health Illn*, (42): 407-422. <https://doi.org/10.1111/1467-9566.13008>

- Crocetti, D., Arfini, E.A.G., Monro, S. and Yeadon-Lee, T. (2020a). ‘You're basically calling doctors torturers’: stakeholder framing issues around naming intersex rights claims as human rights abuses. *Sociol Health*. 42: 943-958. <https://doi.org/10.1111/1467-9566.13072>
- Crocetti, D., Monro, S., Vecchietti, V., & Yeadon-Lee, T. (2020b). Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health. *Culture, Health & Sexuality*, 23(4): 500–515. <https://doi.org/10.1080/13691058.2020.1825815>
- Crocetti, D. (2019). *Rhetoric of Change and Perspectives on Strategic Appeal to International Human Rights Mechanisms* (Interdisciplinary Perspectives on Intersex (IPI2019)). University of Lincoln.
- Davis, G. (2015). *Contesting Intersex: The Dubious Diagnosis*. NYU Press.
- Daston L., & Park K. (1995). “The Hermaphrodite and the Orders of Nature: Sexual Ambiguity in Early Modern France.” *glq: A Journal of Gay and Lesbian Studies* 1 (4): 419–38
- Die Tagespost (10.04.2024). Niederlande rudern bei Selbstbestimmungsgesetz zurück. Retrieved from: <https://www.die-tagespost.de/politik/niederlande-rudern-bei-selbstbestimmungsgesetz-zurueck-art-250024> [Opened on: 01.06.2024, 11.37]
- Feder, E. K. (2021). Feminist theory and intersex activism: Thinking between and beyond. *Philosophy Compass*, 16(10), e12764. <https://doi.org/10.1111/phc3.12764>
- Ginwright, S. A. (2010). Peace out to revolution! Activism among African American youth: An argument for radical healing. *Young*, 18(1): 77–96. doi:10.1177/110330880901800106
- Gunew, S. (1994). *Feminism And The Politics Of Difference* (1st ed.). Routledge. <https://doi.org/10.4324/9780429039010>
- Greenberg, J.A. (1999). “Defining Male and Female: Intersexuality and the Collision between Law and Biology,” *Arizona Law Review* 41(2): 265-328.
- Greenberg, J.A. (2006). Intersex and Intrasex Debates: Building Alliances to Challenge Sex Discrimination. Thomas Jefferson School of Law Research Paper No. 896357, *Cardozo Journal of Law & Gender*, Vol. 13, No. 101, 2006.
- Habarth, J. (2008). *Thinking 'Straight': Heteronormativity and Associated Outcomes Across Sexual Orientation*.

- Hechler, A. (2022). An ideology of erasure: Interphobia in right-wing extremism: A call for intersex-affirmative therapy. *Psychotherapy & Politics International*, 20(3): 1-28. <https://doi.org/10.24135/ppi.v20i3.06>
- Hennink, M., Hutter, I., Bailey, A. (2020): *Qualitative research methods, second edition*. Sage. ISBN 9781473903913
- Holzacker, R.L. (2007). *The Europeanization and Transnationalization of Civil Society Organizations Striving for Equality: Goals and Strategies of Gay and Lesbian Groups in Italy and the Netherlands*.
- Holzacker, R.L. (2012). National and transnational strategies of LGBT civil society organizations in different political environments: Modes of interaction in Western and Eastern Europe for equality. *Comparative European Politics*, 10: 23-47.
- Huckin, T.N. (1997). Critical discourse analysis. In T. Miller (Ed.), *Functional approaches to written text*.
- IDEA International (2023). The Global State of Democracy 2023. The New Checks and Balances. Retrieved from: <https://www.idea.int/publications/catalogue/global-state-democracy-2023-new-checks-and-balances> [Opened on: 15.6.2024, 13.24]
- ILGA Europe (20.02.2023). Annual review of the human rights situation of lesbian, gay, bisexual, trans and intersex people in Europe and Central Asia 2023. Retrieved from: <https://www.ilga-europe.org/report/annual-review-2023/> [Opened on: 1.6.2024, 10.03]
- ILGA Europe (29.02.2024). Annual review of the human rights situation of lesbian, gay, bisexual, trans and intersex people in Europe and Central Asia 2024. Retrieved from: <https://www.ilga-europe.org/report/annual-review-2024/> [Opened on: 1.6.2024, 10.15]
- Jenzen, O. and Lewin, T. (2022). Global Queer and Feminist Activism: An Introduction. *Journal of Cultural Analysis and Social Change*, 7(2): 09. <https://doi.org/10.20897/jcasc/12750>
- Johnson, W. (2003). 'On Agency', *Journal of Social History*, 37(1): 113–24.
- Karkazis, K. (2008). *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. Duke University Press. <https://doi.org/10.1215/9780822389217>
- Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E (2016). The Netherlands: health system review. *Health Systems in Transition*, 2016; 18(2):1–239.



- Lampalzer, U., Briken, P. & Schweizer, K. (2021) Psychosocial care and support in the field of intersex/diverse sex development (dsd): counselling experiences, localisation and needed improvements. *Int J Impot Res* 33, 228–242. <https://doi.org/10.1038/s41443-021-00422-x>
- Locke, T. (2004). *Critical discourse analysis: Critical discourse analysis as research m.* Bloomsbury Publishing Plc.
- LSVD (2021). Schutz intergeschlechtlicher Kinder vor medizinischen Eingriffen. Retrived from: <https://www.lsvd.de/de/ct/5449-Schutz-intergeschlechtlicher-Kinder-vor-medizinischen-Eingriffen> [Opened on 16.6.2024, 20.44]
- Lugones, M. (2003). *Pilgrimages/Peregrinajes: Theorizing Coalition Against Multiple Oppressions*, Rowman & Littlefield Publishers.
- Lugones, M. (2010). Toward a Decolonial Feminism. *Hypatia*, 25(4), 742–759. <http://www.jstor.org/stable/40928654>
- Mansfield, N. (2000). *Subjectivity: Theories of the Self from Freud to Haraway* (New York, NY: New York University Press).
- McNay, L. (2016). “Agency” In *The Oxford Handbook of Feminist Theory*, edited by Lisa Disch and Mary Hawkesworth, New York: Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780199328581.013.2>
- McQueen, P. (2015). Authenticity, intersubjectivity and the ethics of changing sex. *Journal of Gender Studies*, 25(5): 557–570. <https://doi-org.proxy.library.uu.nl/10.1080/09589236.2015.1063991>
- Mendoza, B. (2016). “Coloniality of Gender and Power: From Postcoloniality to Decoloniality.” In *The Oxford Handbook of Feminist Theory*, edited by Lisa Disch and Mary Hawkesworth, New York: Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780199328581.013.6>
- Mestre, Y. (2022). The Human Rights Situation of Intersex People: An Analysis of Europe and Latin America. *Social Sciences* 11: 317. <https://doi.org/10.3390/socsci110703>
- Motschenbacher, H., & Stegu, M. (2013). Introduction: Queer Linguistic approaches to discourse. *Discourse & Society*, 24(5): 519–535. <http://www.jstor.org/stable/24441610>
- Mignolo, W. & Walsh, C. (2018). *On Decoloniality: Concepts, Analytics, Praxis*. 10.1215/9780822371779.

- Ndlovu-Gatsheni, S.J. (2012). Coloniality of power in development studies and the impact of global imperial designs on Africa. *The Australasian review of African studies*, 33: 48-73.
- Ndlovu-Gatsheni, S., J. (2013). Why decoloniality in the 21st Century? *The Thinker*, Vol.48.
- OII Europe (2019). Welcome to the increasingly visible world of intersex people in Europe! Retrieved from <https://intervisibility.eu/> [Opened on: 29.5.2024, 12.31]
- Openly / Thomson Reuters Foundation (22.11.2023). What LGBTQ+ rights are at stake in the Netherlands elections? Retrieved from: <https://www.gaytimes.co.uk/life/what-lgbtq-rights-are-at-stake-in-the-netherlands-elections/> [Opened on 26.1.2024, 12.31]
- Paternotte, D., Hablous, G. & Kraus, C. (2022). Intersex Politics in Europe : Activism, the state, and medical authority. Retrieved from: <https://ecpr.eu/Events/Event/PanelDetails/11465> [Opened on: 27.1.2024, 19.31]
- Philippou, Zoe A. (2019). "Invisible Intersex: How Discourse Serves to Perpetuate Violence" . *Student Publications*. 836.  
[https://cupola.gettysburg.edu/student\\_scholarship/836](https://cupola.gettysburg.edu/student_scholarship/836)
- Quijano, A., & Ennis, M. (2000). Coloniality of Power, Eurocentrism, and Latin America. *Nepantla: Views from South 1*(3), 533-580. <https://www.muse.jhu.edu/article/23906>.
- Roth, K. (23.01.2015). LGBT: Moving Towards Equality. Retrieved from <https://www.hrw.org/news/2015/01/23/lgbt-moving-towards-equality> [Opened on: 03.6.2024, 09.31]
- Rubin, D.A. (2015). Provincializing Intersex: US Intersex Activism, Human Rights, and Transnational Body Politics. *Frontiers: A Journal of Women Studies*, 36(3), 51–83. <https://doi.org/10.5250/fronjwomestud.36.3.0051>
- Rubin, D. A. (2017). *Intersex Matters: Biomedical Embodiment, Gender Regulation, and Transnational Activism*. USA: State University of New York Press.
- Ryan, G.W. and Bernard, H.R. (2010) *Analyzing Qualitative Data: Systematic Approaches*. Thousand Oaks, CA: Sage Publications.
- Scheidler, T. R. , Haus, K.R. , Mobley, T.A. & Mark, K. P. (2023). LGBTQ+ Grassroots Activism: An Opportunity for Resilience, *Journal of Homosexuality*, 70:9, 1675-1700, DOI: 10.1080/00918369.2022.2040928

- Schmitt, F. E., and Patricia Yancey M. (1999). “Unobtrusive Mobilization by an Institutionalized Rape Crisis Center: ‘All We Do Comes from Victims.’” *Gender & Society* 13(3): 364–84
- Schotel, A.L. (2023). Mainstream or Marginalized? How German and Dutch Newspapers Frame LGBTI, *Social Politics: International Studies in Gender, State & Society*. 30(2): 444–469, <https://doi.org/10.1093/sp/jxac004>
- Snow, D. A., Vliegenthart, R., & Ketelaars, P. (2019). The framing perspective on social movements: Its conceptual roots and architecture. In D. A. Snow, S. A. Soule, H. Kriesi, & H. J. McCammon (Eds.), *The Wiley Blackwell Companion to Social Movements* (2nd ed., pp. 392-410). (Wiley Blackwell companions to sociology). Wiley Blackwell. <https://doi.org/10.1002/9781119168577.ch22>
- Stitching OpenMind (2023). Intersex portraits. Retrieved from: <https://www.stichtingopenmind.nl/intersex-portraits/> [Opened on: 27.3.2024, 14.12]
- Van Young, E (2001). *The Other Rebellion: Popular Violence, Ideology, and the Mexican Struggle for Independence*. 1810–1821 Stanford, CA: Stanford University Press).
- Van Lisdonk, J. (2014). *Living with intersex/DSD: An exploratory study of the social situation of persons with intersex/DSD*.
- Von Molitor, M. (01.06.2015). Im Raster der Zweigeschlechtlichkeit. Die gefährlichen Intersex-Gentests. Retrieved from: <https://www.tagesspiegel.de/gesellschaft/queerspiegel/die-gefaehrlichen-intersex-gentests-3631285.html> [Opened on: 16.5.2024, 13.05]
- Von Wahl, A. (2019). From Object to Subject: Intersex Activism and the Rise and Fall of the Gender Binary in Germany, *Social Politics: International Studies in Gender, State & Society*. 28(3): 755–777, <https://doi.org/10.1093/sp/jxz044>
- Walker, M. (2022). Introduction. In: Walker, M. (eds.) *Interdisciplinary and Global Perspectives on Intersex*. Palgrave Macmillan, Cham. [https://doi.org/10.1007/978-3-030-91475-2\\_1](https://doi.org/10.1007/978-3-030-91475-2_1)
- Warsi, Z., Hastings, D. (14.06.2022). Why far-right groups are increasingly targeting the LGBTQ community. Retrieved from: <https://www.pbs.org/newshour/show/why-far-right-groups-are-increasingly-targeting-the-lgbtq-community> [Opened on: 13.5.2024, 12.00]

Wengraf, T. (2001) *Qualitative Research Interviewing: Biographic Narrative and Semi-Structured Methods*. Sage Publications, London, 7. <https://doi.org/10.4135/9781849209717>

Wiesner, A. (2012). *LGBTQ Activism and the Appropriation of Queer Theory in Spain*.

Wolff, M., Rubin, D.A, Lock Swarr, A (2022). The Intersex Issue: An Introduction. *TSQ* 1 May 2022; 9 (2): 143–159. doi: <https://doi.org/10.1215/23289252-9612767>

Zelayandia-Gonzalez, E. (2023). "The Growing Visibility of Intersex Demands at the United Nations: A Review of the Treaty Bodies' Concluding Observations" *Social Sciences* 12(2): 73. <https://doi.org/10.3390/socsci12020073>

Zeeman, L., Sherriff, N., Browne, K., McGlynn, N., Mirandola, M., Gios, L., Davis, R., Sanchez-Lambert, J., Aujean, S., Pinto, N., Farinella, F., Donisi, V., Niedźwiedzka-Stadnik, M., Rosińska, M., Pierson, A., Amaddeo, F., & Health4LGBTI Network (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European journal of public health*, 29(5): 974–980. <https://doi.org/10.1093/eurpub/cky226>

## References Ethical consent form

Nariman, M. & Domingus, M. (March, 2017). Standard EUR Informed Consent Form template version 0.2. Erasmus University Rotterdam. Conducted from: [https://www.eur.nl/sites/corporate/files/2017-11/Standard\\_EUR\\_Informed\\_Consent\\_Form\\_template\\_v.0.2.\\_201703.docx](https://www.eur.nl/sites/corporate/files/2017-11/Standard_EUR_Informed_Consent_Form_template_v.0.2._201703.docx) [Opened on: 12.2.2024, 14.03]

University of Edinburgh (2013). Interview Consent Form. Retrieved from: [https://www.ed.ac.uk/files/imports/fileManager/Interview\\_Consent\\_Form.pdf](https://www.ed.ac.uk/files/imports/fileManager/Interview_Consent_Form.pdf) [Opened on: 11.2.2024, 13.07]

Utrecht University. How to write an informed consent form. Conducted from: <https://www.uu.nl/en/research/research-data-management/guides/legal-considerations/how-to-write-an-informed-consent-form> [Opened on: 12.2.2024, 15.12]

## References Critical Discourse Analysis

AGS-Eltern- und Patienteninitiative e.V. (2017). “Die unschlimmste Krankheit, die man sich vorstellen kann” AGS (Adrenogenitales Syndrom). Retrieved from: <https://empower->

[dsd.charite.de/fileadmin/user\\_upload/microsites/forschungsprojekte/empower-dsd/AGS\\_Die\\_unschlimmste\\_Krankheit...pdf](https://dsd.charite.de/fileadmin/user_upload/microsites/forschungsprojekte/empower-dsd/AGS_Die_unschlimmste_Krankheit...pdf) [Opened on: 01.5.2024, 14.56]

Antidiskriminierungsarbeit & Empowerment für Inter\* (2016). Medizinische Eingriffe an Inter\* und deren Folgen: Fakten & Erfahrungen. Retrieved from: [https://inter.transinterqueer.org/wp-content/uploads/2021/11/Inter\\_Eingriffe\\_Folgen\\_barrierefrei.pdf](https://inter.transinterqueer.org/wp-content/uploads/2021/11/Inter_Eingriffe_Folgen_barrierefrei.pdf) [Opened on: 23.5.2024, 17.22]

Ghattas, D.C., Kromminga, I.A., Matthigack, E.B., Mosel, E.T (2015). Inter\* & Sprache. Von “Angeboren” bis “Zwitter”. Retrieved from: [https://inter.transinterqueer.org/wp-content/uploads/2021/05/InterUndSprache\\_A\\_Z.pdf](https://inter.transinterqueer.org/wp-content/uploads/2021/05/InterUndSprache_A_Z.pdf) [Opened on: 02.5.2024, 10.04]

Gijben, L. 30 Years of Intersex in Dutch Newspapers: The slow shift from a medical framework to a human rights framework Nijmegen, Nederland: Stichting NNID, 2021. Rapport Nr. 2021-01, ISBN 978-94-93106-04-8

ILGA Europe (2023). Annual review of the human rights situation of lesbian, gay bisexual, trans, and intersex people in the Netherlands, covering the period of January to December 2022. Retrieved from: Retrieved from: <https://www.ilga-europe.org/sites/default/files/2023/netherlands.pdf> [Opened on: 1.6.2024, 10.03]

Intergeschlechtliche Menschen e.V. (without year). Wissen. Beratung. Selbsthilfe. Rechte. Wissen, Beratung, Selbsthilfe und Rechte für intergeschlechtlich geborene Menschen, ihre Familien und Angehörigen sowie ihr weiteres Umfeld. Retrieved from: [https://im-ev.de/wp-content/uploads/2021/06/Broschuere\\_IMeV\\_web.pdf](https://im-ev.de/wp-content/uploads/2021/06/Broschuere_IMeV_web.pdf) [Opened on: 02.5.2024, 13.23]

OII Europe (22.10.2021). Towards an evaluation of the Victims’ Rights Directive. Retrieved from: [https://www.oii-europe.org/wp-content/uploads/2021/10/OII-Europe-Submission-Victims-Rights-Directive\\_FINAL.pdf](https://www.oii-europe.org/wp-content/uploads/2021/10/OII-Europe-Submission-Victims-Rights-Directive_FINAL.pdf) [Opened on: 24.4.2024, 12.12]

OII Europe (2019). #MyIntersexStory Personal accounts by intersex people living in Europe. Retrieved from: [https://www.oii-europe.org/wp-content/uploads/2019/11/testimonial\\_broch\\_21-21cm\\_for\\_web.pdf](https://www.oii-europe.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf) [Opened on: 27.5.2024, 16.55]

TransInterQueer e.V. & Verein intergeschlechtlicher Menschen Österreich (2020). Inter\* Informationen für Ärzt\_innen, Therapeut\_innen & andere pflegende und medizinische Berufsgruppen. Retrieved from: <https://inter.transinterqueer.org/wp->

[content/uploads/2021/06/InterAerzt\\_innen\\_barrierefrei.pdf](#) [Opened on: 03.5.2024, 09.07]

Träbert, A. (2022). Leitfaden für die Praxis. LSBTI\* Sensiblergewaltschutz für Geflüchtete.  
Retrieved from: [https://www.gewaltschutz-gu.de/fileadmin/user\\_upload/PDFs\\_Publikationen\\_/Praxisleitfaden2Auflage2022.pdf](https://www.gewaltschutz-gu.de/fileadmin/user_upload/PDFs_Publikationen_/Praxisleitfaden2Auflage2022.pdf)  
[Opened on: 29.5.2024, 17.07]

## Appendix

Due to the protection of the personal information of the participants, the transcripts, interview guides, and summaries can only be accessed after contacting the main researcher. Please reach out to [leonie.k.fischer@gmx.net](mailto:leonie.k.fischer@gmx.net)

Also, reach out for more information on the coding process, the rationale of the document choice, and the overview of used documents.