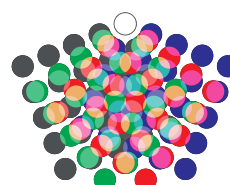


# 30 Years of Intersex in Dutch Newspapers

**The slow shift  
from a medical framework  
to a human rights framework**



A study commissioned by  
**Stichting NNID, Nederlandse organisatie voor seksediversiteit**



**NNID**  
NEDERLANDSE ORGANISATIE  
VOOR SEKSE DIVERSITEIT

# 30 Years of Intersex in Dutch Newspapers

The slow shift from a medical framework to a human rights framework

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# Samenvatting Nederlands

## **“Het is geen medisch probleem, maar een cultureel probleem”**

*Een onderzoek naar de invloed van de Nederlandse interseksebeweging op maatschappelijke discourses in de Nederlandse media*

Samenvatting van: Gijben, L. (2021). *“It is not a medical problem, it is a cultural problem”: A case study on the amount of media influence by the intersex movement in the Netherlands*. Radboud Universiteit Nijmegen.

Intersekse is lange tijd alleen beschouwd als een medisch probleem totdat de interseksebeweging dit medische frame ging aanvechten vanuit een mensenrechtenperspectief. De interseksebeweging, zowel in Nederland als daarbuiten, probeert discourses<sup>1</sup> met betrekking tot intersekse te veranderen. Bij het begin van het hier gepresenteerde onderzoek was het echter onduidelijk in hoeverre de Nederlandse interseksebeweging succesvol is in het onder de aandacht brengen van het mensenrechtenperspectief in de Nederlandse media. De hoofdvraag van dit onderzoek is daarom: in welke mate heeft de Nederlandse interseksebeweging discourses over intersekse in de Nederlandse media beïnvloed?

### **De Nederlandse interseksebeweging**

De eerste deelvraag van dit onderzoek is: wanneer is de Nederlandse interseksebeweging ontstaan en hoe heeft deze zich ontwikkeld? Deze vraag is onderzocht aan de hand van secundaire bronnen, zoals websites van intersekseorganisaties en lhbt-organisaties in Nederland. Om te bepalen in hoeverre de Nederlandse interseksebeweging een sociale beweging is, zijn verschillende sociale beweging theorieën onderzocht en is een definitie opgesteld op basis waarvan de interseksebeweging getoetst kan worden. Deze definitie luidt: een sociale beweging is een maatschappelijk instituut dat door mensen of organisaties ingezet wordt om sociale of politieke verandering te bewerkstelligen op basis van een gedeelde identiteit. Sociale bewegingen opereren over het algemeen buiten institutionele contexten. Ze zijn meestal georganiseerd en werken samen met andere organisaties, groepen of individuen in een groter netwerk. Sociale bewegingen bestaan bijna altijd voor een langere periode (zie paragraaf 2.1.2).

Daarnaast moest onderzocht worden welke organisaties behoren tot de interseksebeweging in Nederland. Om dat te bepalen zijn definities opgesteld van verschillende organisaties die in een sociale beweging kunnen participeren. Een sociale beweging organisatie (SBO) is een formele organisatie die zich identificeert met de ideeën en belangen van de sociale beweging<sup>70</sup>. Een patiëntenorganisatie (PO) is een organisatie die zich inzet om het leven van mensen met een beperking of ziekte te verbeteren<sup>58, 73, 93</sup>. Het belangrijkste doel van een PO is het creëren van een gezamenlijke identiteit en een netwerk van ondersteuning<sup>73, 93</sup>. Een belangengroep (BO) is een organisatie die de politiek probeert

te beïnvloeden door informele interactie te bewerkstelligen met beleidsmakers<sup>7, 10</sup>. Er bestaan verschillen tussen SBOs, POs en BOs, maar deze organisaties kunnen wel dezelfde doelen hebben, en zich verenigen in een sociale beweging coalitie. Zij kunnen er dan voor kiezen om samen te werken en zo de politiek en/of andere instituties te beïnvloeden<sup>95</sup>.

De interseksebeweging<sup>2</sup> in Nederland bestaat uit de volgende organisaties: Bijniervereiniging-NVACP (PO), Nederlandse Klinefelter Vereniging (PO), Stichting MRK-Vrouwen (PO), Turner Contact Nederland (PO), DSDNederland (PO) en NNID (SBO/BO). Contactgroep Triple-X Syndroom is te classificeren als een patiëntenondersteuningsgroep (zie paragraaf 4.2). Daarnaast vormt NNID samen met COC Nederland en Transgender Netwerk Nederland een alliantie, gebaseerd op een gezamenlijke veranderingstheorie<sup>81</sup>.

### **Onderzoek naar mediadiscourses**

De tweede deelvraag onderzoekt de discourses in de Nederlandse media: welke discourses over intersekse zijn er te vinden in Nederlandse kranten? Deze vraag is beantwoord door middel van een Critical Discourse Analysis (CDA). Met een CDA kan worden onderzocht welke discourses gebruikt worden, wie verantwoordelijk zijn voor het gebruik van deze discourses en wie de macht heeft om deze discourses te bepalen<sup>129, 130</sup>. Kranten zijn gekozen als onderzoeksobject omdat kranten toegankelijk zijn voor de meeste Nederlanders en kranten in de Nederlandse samenleving een belangrijke rol spelen in het maatschappelijke discours<sup>83</sup>.

Sociale bewegingen willen politieke verandering bewerkstelligen en daarvoor moeten zij hun belangen op de politieke agenda zien te krijgen. Eén van de manieren om dit te doen, is door het maatschappelijke discours te beïnvloeden en ervoor te zorgen dat er in de media gepraat wordt over jouw onderwerp<sup>4</sup>. Politici en beleidsmakers gebruiken namelijk wat er in de media wordt besproken, om te bepalen welke onderwerpen op de politieke agenda moeten komen te staan<sup>52</sup>. Het probleem is echter dat er sprake is van asymmetrische afhankelijkheid: sociale bewegingen zijn veel afhankelijker van de media dan dat de media afhankelijk is van hen<sup>19, 54</sup>. De media bepalen voor een groot deel zelf wie zij aan het woord laten en welke betekenis zij geven aan maatschappelijke gebeurtenissen<sup>52, 53</sup>. SBO's kunnen wel middelen genereren om meer media-aandacht te krijgen, zoals geld of contact leggen met journalisten. Ook onderdeel zijn van een grotere coalitie met andere SBO's kan de kans op media-aandacht vergroten, omdat je als individuele organisatie de middelen van andere organisaties kan benutten<sup>4, 54</sup>.

Om te meten in hoeverre sociale bewegingen succesvol zijn in het genereren van media-aandacht, kijken we naar drie zaken: zichtbaarheid, stand hebben, en framing.<sup>3</sup> Voor het onderzoek zijn artikelen gebruikt van zes Nederlandse kranten: De Telegraaf,

1 Discourses zijn de verzameling van ideeën, concepten en categorieën die betekenis geven aan sociale fenomenen<sup>57</sup>. Discourses helpen ons om betekenis te geven aan de wereld om ons heen<sup>51</sup>. Discourses worden gecommuniceerd via teksten, gesprekken, afbeeldingen, en lichaamstaal<sup>130</sup>.

2 De term intersekse wordt niet door alle organisaties zelf gebruikt, maar met het oog op de helderheid voor het onderzoek worden de organisaties, op basis van de beschreven definities, gecategoriseerd binnen de interseksebeweging.

3 Zichtbaarheid slaat op hoe vaak een onderwerp of een actor is benoemd in de media. Stand hebben betekent dat een organisatie wordt beschouwd als een serieuze actor met betrekking tot een specifiek onderwerp<sup>53</sup>. In dat geval is de kans groter dat de actor direct of indirect geciteerd wordt in de media<sup>142</sup>. Framing betekent dat de SBO in staat is om een onderwerp of gebeurtenis op haar manier te belichten, om op die manier het maatschappelijke discours te

Trouw, de Volkskrant, AD/Algemeen Dagblad, NRC Handelsblad en Het Parool. Op basis van een woordenlijst zijn artikelen gezocht via de LexisNexis krantendatabase tussen 1991 en 2020. Het onderzoek richtte zich specifiek op het aantal artikelen dat per jaar is verschenen over intersekse (zichtbaarheid), de directe en indirecte citaten van relevante actoren binnen en buiten de intersekse-beweging (stand hebben), en welk frame werd gebruikt in het artikel: het medische frame of het mensenrechtenframe<sup>4</sup> (framing).

## Resultaten

De resultaten van het onderzoek laten zien dat intersekse sinds 1991 zichtbaarder is geworden in het maatschappelijke discours, met een duidelijke stijging vanaf 2017. Dit komt mede door de toevoeging van de 'i' aan de lhbtj-afkorting. Daarnaast kunnen we stellen dat het mensenrechtenframe vanaf 2017 dominant is geworden dan het medische frame. Tot 2017 had het medische frame altijd de overhand, maar na 2017 is dit omgedraaid. Tegelijkertijd is het medische frame nog steeds aanwezig in het maatschappelijke discours in de media. Uit de analyse blijkt ook dat wanneer een organisatie zoals NNID aan het woord is, zij in staat is om het mensenrechtenframe uit te dragen. Als NNID meer stand genereert bij de media, kan dit er dus toe leiden dat het mensenrechtenframe nog zichtbaarder wordt in de media. Ook hun samenwerking met organisaties als COC Nederland en Transgender Netwerk Nederland heeft een positief effect gehad op de zichtbaarheid van intersekse. Een sociale beweging coalitie kan dus een SBO helpen om meer middelen te genereren en een groter

netwerk op te bouwen, om zo de asymmetrische afhankelijkheid te omzeilen.

Het antwoord op de hoofdvraag is dat de interseksebeweging in Nederland tot op zekere hoogte in staat is geweest op het maatschappelijke discours in de Nederlandse media te beïnvloeden, omdat uit het onderzoek blijkt dat intersekse zichtbaarder is geworden in Nederlandse kranten en het mensenrechtenframe meer aanwezig is sinds 2017. Tegelijkertijd is het niet zo dat de gehele intersekse beweging media-aandacht heeft weten te genereren, alleen NNID wordt regelmatig genoemd als relevante actor. Maar ook NNID heeft nog geen volledige stand verkregen bij de media, en moet zich hier dus nog actief voor inzetten. De vraag blijft ook in hoeverre de algemene maatschappelijke discussie over lhbtj-onderwerpen invloed heeft gehad op de discourses over intersekse, of dat de intersekse discourses invloed hebben gehad op discourses over lhbtj-gerelateerde zaken.

Al met al laat dit onderzoek zien dat intersekseonderwerpen steeds meer aandacht krijgen in de Nederlandse media, en dat deze aandacht ook steeds meer vanuit een mensenrechtenperspectief gebeurt. Echter, zolang medische professionals nog tegelijkertijd aan het woord komen wanneer het intersekse betreft, bevestigt dit het beeld dat intersekse inderdaad iets medisch is. Het gevolg is dat NNID zich nog altijd moet inzetten om het mensenrechtenperspectief onder de aandacht te brengen.

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beïnvloeden[8]. Als een organisatie geciteerd wordt in de media, is de kans ook aanzienlijk groter dat het voorkeursframe van de organisatie wordt overgenomen.

4 In de hiernavolgende Engelstalige tekst wordt uitgebreid ingegaan op deze twee frames. De belangrijkste verschillen staan opgesomd in Tabel 3.2.

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## List of abbreviations

|              |  |
|--------------|--|
| <b>AIS</b>   | Androgen Insensitivity Syndrome  |
| <b>CAH</b>   | Congenital Adrenal Hyperplasia   |
| <b>CDA</b>   | Critical Discourse Analysis  |
| <b>DSD</b>   | Disorders of Sex Development   |
| <b>ISNA</b>  | Intersex Society of North America  |
| <b>LGBTI</b> | Lesbian, Gay, Bisexual, Transgender, Intersex  |
| <b>MRKH</b>  | Mayer-Rokitansky-Küster-Hauser (syndrome)  |
| <b>NNID</b>  | Nederlandse Organisatie voor Seksediversiteit ( <i>Netherlands Network Intersekse/DSD</i> );<br>Netherlands Organisation for Sex diversity ( <i>Netherlands Network Intersex/DSD</i> ) |
| <b>NVACP</b> | Nederlandse Vereniging voor Addison en Cushing Patiënten ( <i>Dutch Association for Addison and Cushing patients</i> )   |
| <b>OHCHR</b> | The Office of the High Commissioner for Human Rights   |
| <b>PPT</b>   | Political Process Theory   |
| <b>RMT</b>   | Resource Mobilisation Theory   |
| <b>SMO</b>   | Social Movement Organisation   |
| <b>TNN</b>   | Transgender Network Nederland (Transgender Network the Netherlands)  |
| <b>US</b>    | United States  |
| <b>VSOP</b>  | Vereniging Samenwerkende Ouder- en Patiëntenorganisaties<br>( <i>Association Collaborating Parent- and Patient organisations</i> )   |

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## Summary

Intersex issues are understudied from a social scientific perspective. Therefore, this research aims to shed light on public discourses about intersex (issues) in the Dutch media, thereby filling a gap in our current knowledge about how intersex is discussed and perceived in society. For a long time, intersex was solely perceived as a medical issue, until the intersex movement started to challenge this medical frame with a human rights frame. The question is to what extent the intersex movement has been successful in changing the framing of intersex issues in Dutch newspapers. This question has been examined with the use of desk research and critical discourse analysis.

The results demonstrate that the intersex movement in the Netherlands has become more visible in the media since 2017. The framing of intersex issues largely depends on who is 'having standing': who is perceived by the media as a relevant actor. While the intersex movement has increased its standing over the last thirty years, medical professionals have lost part of their authority over the issue. As a consequence, the human rights frame became more visible in the public discourse. The social movement coalition between the intersex movement and other LGBTI organisations has

also enlarged the visibility and standing of the intersex movement. These results indicate that to increase the likelihood of successfully impacting the framing in the public discourse, a social movement has to attract standing with the media and become part of a social movement coalition.

This research has given insight into to what extent NNID has been able to reach its strategic goals that have been set out in 2017. If we look specifically at the impact of NNID on public discourses about intersex, the results show that the organisation has been able to make both the organisation itself and intersex issues more visible. Moreover, the organisation has been able to attract some standing with the media. At the same time, NNID still has to gain more consistent standing with the media, meaning that they have to continue trying to become seen as a relevant spokesperson regarding intersex issues. Coalitions with other LGBTI organisations have had a positive influence on the visibility of intersex, however, NNID has to continue to actively raise awareness for intersex issues to avoid losing authority over the subject.

## Foreword

Representation. Recognition. Change. These things are tremendously important for the intersex community. NNID has been working on improving the representation and visibility of intersex people in Dutch society since 2013. Although their work has been indispensable, they cannot do it alone. Civil society plays a significant role in the acceptance and recognition of intersex people and their lives. The media specifically has a lot of influence. The amount of media attention and the kind of media attention impacts the representation and recognition of the intersex community, which could eventually lead to policy changes on a political level. Based on the conversations I have had with intersex people during my internship, the media can have a very positive influence on their outlook on the world and how they view themselves. At the same time, the lack of representation and the amount of misinformation about intersex harms the community and hinders the path to change.

This publication aims to demonstrate the results of the research I conducted, commissioned by NNID, to public discourses about intersex in the Dutch media. This report, in combination with a survey and a think tank, forms the foundation for the upcoming media guide for journalists and other media professionals. This research shows that although much has changed in the past few years, there is still a lot of work to do when it comes to the visibility

and representation of intersex issues in the media. As long as the medical frame remains dominant in the media, the human rights frame will be underexposed. If the human rights frame continues to be more and more articulated in the public discourse, the hope is that the underrepresentation and invisibility of intersex people and their lives will reduce. It is time to shed light on a group of people that have had to hide in the shadows for so long and to acknowledge the need for a human rights perspective on intersex issues.

Before you start to read, I want to take a moment to thank some people. First of all, my colleagues at NNID, and especially Bente Keulen, for their support and advice. I want to thank Prof. Dr. Anna van der Vleuten from the Radboud University of Nijmegen, who has been my supervisor during this research and who has guided me through this process. I hope that this research will help to fulfil NNID's goals and that it contributes to the making of an intersex-inclusive society.

Lisanne Gijben

Hoorn, October 20, 2021





# 1. Introduction

In an Instagram post on May 5th 2021, Raven van Dorst announced that they are non-binary<sup>[133]</sup>. The Dutch singer and television maker had already revealed in 2017 that they were intersex in their television program.<sup>5</sup> Both announcements sparked media attention for intersex issues, but the attention was only momentary. In general, changes regarding society's view upon the strict sex and gender binary are visible in society. For example, in 2018, a Dutch court ruled that a woman who was born intersex was allowed an 'X' in her official governmental documents. The court recognised that society was changing. According to the judge, the gender identity and expression of the individual were considered more important than what her body looked like<sup>[100, 127]</sup>. This case also caused national attention for intersex issues in the media, but there is still a lot of ignorance surrounding the topic. Recent research by van Ditzhuizen and Motmans indicated that almost 50 per cent of Dutch respondents did not know what the term intersex meant, and only 8 per cent had seen an intersex person in the media<sup>[131]</sup>.

NNID has found it important that intersex issues are discussed in the media, and that it becomes a regular topic in the public discourse. However, the way intersex issues are discussed does matter for how intersex issues are perceived in civil society. Since the 1990s, the intersex movement has tried to frame intersex issues as a human rights problem, thereby fighting the medical frame that has been dominant in the public discourse. To gain a better understanding of to what extent the intersex movement has been successful in influencing public discourse, this research has aimed to answer the question: *to what extent did the intersex movement in the Netherlands influence the discourses about intersex in the Dutch media?* This publication will shed light on whether the Dutch media has shifted its framing of intersex issues from a medical to a human rights frame under the influence of the intersex movement.

## 1.1. Sub-questions and research design

A longitudinal case study research design has been used to investigate the development of the media influence by the intersex movement over thirty years. The first sub-question is: *When did the intersex movement emerge in the Netherlands and how did it develop?* This question has been answered by the use of desk research using secondary sources to provide an overview of the development of the different organisations within the movement.

The second sub-question is: *What discourses do Dutch newspapers construct surrounding intersex?* To answer this question, a critical discourse analysis (CDA) has been conducted. A CDA allows looking at which discourses are being constructed, who is responsible for those discourses and who has the power to construct those discourses. To analyse discourses in the media, newspaper articles have been chosen as the unit of observation because newspapers are easily available to everyone and play an important role in producing the public discourse<sup>[83]</sup>. The CDA aims to uncover the relationship between the amount of visibility, standing and framing of the intersex movement and the discourses about intersex in the Dutch media.

First, visibility looks at how much media coverage intersex has received since 1991 and whether this attention has grown during the development of the movement. Second, 'having standing' means whether an actor is considered an important actor by the media. When this is the case, an actor is often quoted in newspaper articles, which means that the actor can influence the framing of a certain issue. Third, framing refers to what frame the media use when they write about intersex: a medical frame or a human rights frame. The intersex movement disagrees with the medical practices used by doctors to 'normalise' the bodies of intersex children. They argue that such operations are a violation of the bodily integrity of children and can be considered torture. While medical professionals try to fit intersex bodies in the male-female binary, intersex activists argue that this is an unnecessary practice and that society should change its strict binary standards about male and female bodies. These different standpoints will be further explained in Chapter 4.

## 1.2. Relevance

The relevance of this research is two-fold. First of all, this research has provided NNID with an extensive overview of the developments of the last thirty years in the Dutch (written) media regarding intersex issues. This general oversight gives a good indication of how the public discourse regarding intersex has developed, and also where it is at now.

Second, the results of this research have also shown NNID to what extent they have been able to influence the public discourse themselves. The results have indicated which interventions by NNID have had a positive influence, and where intervention is still necessary. The next step is to consider what measures have to be taken to further increase the media attention for intersex issues and change the framing of intersex issues. The research both justifies and guides the work of NNID.

## 1.3. Reading guide

The remainder of this publication is structured as follows. The next chapter contains the theoretical framework, in which the current theories regarding social movements are discussed which provides a clear framework to determine which organisations are part of the intersex movement. This chapter also demonstrates why and how social movements use the media to influence the public discourse, and which aspects can measure the success of these strategies. The third chapter discusses the research method used to answer the research question. The fourth chapter answers the first sub-question and provides an overview of the various organisations in the intersex movement and their relationship with each other. The fifth chapter demonstrates the results of the second sub-question and discusses which discourses have been identified through the discourse analysis, as well as how the framing of intersex issues has developed over time. The final chapter discusses the main findings of this research, provides an answer to the main question and gives recommendations for further research.

5 Van Dorst uses the non-binary pronouns 'they/them'.

## 2. Theoretical framework

There is a huge lack of research regarding intersex issues, especially from a social scientific point of view, which is why it is not surprising that no systematic overview of the intersex movement in the Netherlands is available. Therefore, the first sub-question will investigate how the Dutch movement emerged and developed. To answer this question, this theoretical framework will be used to classify the movement and its organisations in Chapter 4. In this chapter, the definitions of a social movement, a social movement organisation (SMO), a patient organisation, and an interest group will be discussed. In the second part, the relationship between social movements and the media will be discussed.

### 2.1. Social movement theories

#### 2.1.1. Resource Mobilisation Theory and Political Process Theory

To define a social movement, a few theories have to be discussed that together provide a conceptual framework of what a social movement entails. First of all, the Resource Mobilisation Theory (RMT) emphasises the rational character of social movements and argues that they emerge out of a need to change social or political structures in society<sup>[39]</sup>. Moreover, the theory looks at the requirements that are necessary for a group of people to turn their opinions and beliefs into collective action. Resources are the most important tool to be able to do so. Resources include things such as human time, effort or money<sup>[49]</sup>.

Secondly, Political Process Theory (PTT) seeks to explain the political context in which social movements arise. According to PTT, a social movement aims to challenge power structures in society by publically urging change by using informal means, such as protests, and to represent those who are not formally represented, such as in parliament. The PTT sees social movements as an organised manner to challenge the current political system based on a collective identity<sup>[39]</sup>.

To explain the emergence and development of social movements, scholars combined the RMT and the PTT. According to McAdam, McCarthy and Zald, three aspects are relevant for the emergence and development of social movements. These aspects relate to how social movements can be defined. First, political opportunities relate to the political opportunities and restrictions in national settings that influence the emergence and development of social movements<sup>[69]</sup>. According to Morris, opportunities appear when, for example, new cleavages emerge between political elites or when new allies emerge in or outside the political arena<sup>[75]</sup>. McAdam, McCarthy and Zald argue that many social movements have emerged when the political order is considered to be unprotected or more open for change than usual<sup>[69]</sup>.

Second, mobilising structures are the means social movements use to mobilise people to engage in collective action<sup>[69]</sup>. In other words, mobilising structures are the resources a social movement needs to be able to change social, political and power structures. Edwards and McCarthy distinguish between moral resources (e.g. legitimacy, solidarity), cultural resources (e.g. knowledge about how to organise a protest, how to get access to journalists), social-organisational resources (e.g. recruiting volunteers), human resources (e.g. labour, skills) and material resources (e.g. money,

office space)<sup>[49]</sup>. To attract and use resources in an effective way, it is important that the movement is professionally organised and has decisive leadership<sup>[39, 69]</sup>.

The third aspect is framing processes. This aspect looks at the shared understandings between people that makes them demand change. A social movement can engage in strategic action to create a shared understanding of the issues at stake, which can help to mobilise people to engage in collective action<sup>[69]</sup>. Framing processes can be seen as a process of identity formation. A social movement can create a collective identity, which sets the boundaries of who belongs to the social movement and who does not<sup>[39]</sup>. Moreover, by creating a collective identity, the social movement can let other people know what they stand for and what they want to change<sup>[144]</sup>.

#### 2.1.2. Defining a social movement

Diani argues, based on these theories, that a social movement can be defined as groups or organisations that aim to induce political or cultural change, based on a collective identity<sup>[39]</sup>. More importantly, he adds to this definition that social movements consist of “networks of informal interactions”<sup>6</sup> between organisations, groups and individuals. According to Diani, these networks are necessary to attract resources and further clarify and specify the issues at stake<sup>[39]</sup>.

Whereas Diani’s definition highlights the networked character of social movements, the RMT and the PTT focus on what conditions are necessary for a movement to emerge, such as resources and a collective identity. Snow argues that these definitions do not exclude each other, rather they simply emphasise one particular aspect of a social movement over another. Therefore, Snow combines these different aspects and argues that six main elements can be used to define a social movement<sup>[102]</sup>.

Social movements:

- i. seek or resist change;
- ii. challenge institutional and political structures;
- iii. act collectively;
- iv. act outside of institutional structures (in various forms);
- v. are organised to some extent (either in the form of one single organisation or in a network of multiple organisations);
- vi. tend to last for a longer time<sup>[102]</sup>.

Taking these different approaches and definitions into consideration, it can be argued that social movements are the social institution through which groups of people or organisations seek or resist social and/or political change based on a shared collective identity. By undertaking collective action, a social movement challenges institutional structures. Social movements usually operate outside of institutional contexts. They are often organised and have professional leadership, and they frequently work in larger networks of multiple (in)formal organisations, groups and individuals. Social movements commonly stick around for a longer period.

6 Diani, M. (1992, p. 8). The concept of social movement. *The Sociological Review*, 40(1), 1–25. <https://doi.org/10.1111/j.1467-954X.1992.tb02943.x>

## 2.2. Social movement organisations

Now that we have defined what a social movement is, we can turn to SMOs. This concept is useful to distinguish between the different organisations within a movement. We can define an SMO as a: “formal organization that identifies its preferences with a social movement”<sup>7</sup>. Social movements can consist of several formal organisations that are fighting for the same cause<sup>[39]</sup>. Two types of SMOs will be discussed here: patient organisations and interest groups.

### 2.2.1. Patient organisations

Patient organisations originate out of the need from a group of people (usually patients themselves) to deal with a particular disease or disability and find ways to improve their well-being<sup>[73]</sup>. Therefore, the main goal of a patient organisation is to influence and improve the health care of the represented patient group<sup>[58, 73, 84, 93]</sup>. According to Peeters et al., this is done by trying to put the patients’ health care on the medical and/or political agenda and influencing decision-making processes<sup>[84]</sup>. Another significant aspect of the work of patient organisations is building a collective identity among patients and creating a strong support network<sup>[84, 93]</sup>. Patient organisations play an important role in connecting patients with each other by organising events, writing newsletters or providing an online forum<sup>[58]</sup>. Patient organisations are usually formally organised and non-profit based<sup>[73, 93]</sup>. Like social movements, they seek change in a collective manner. They generally operate outside of the political arena and induce change by operating in and making use of a network of other peer support groups, health care professionals and researchers<sup>[58, 67]</sup>.

### 2.2.2. Interest groups

A second specific kind of SMO is an interest group. Defining an interest group has been a difficult task for scholars<sup>[7, 10]</sup>. Baroni et al. argue that the literature makes a distinction between organisational characteristics and observable, policy-related activities. The former highlights the organisational characteristics and considers only membership-based organisations as interest groups. The ‘voluntary stereotype’ is a pitfall of this approach, as it assumes that all interest groups are “voluntary, democratically accountable and individual-based organisations”<sup>8</sup>, which makes it seem like all interest groups are advantageous for democracy<sup>[7]</sup>. The latter defines interest groups as “any group acting, or tending toward action”<sup>9</sup>. Scholars from this group argue that membership-based interest groups only form a small portion of all the interest groups out there. At the same time, this definition does not seem to have any boundaries: little political activity is enough to be perceived as an interest group<sup>[7]</sup>.

To summarise the key arguments in the literature, Beyers et al. argue that three key factors are central to what is considered as an interest group: organisation, political interest and informality<sup>[10]</sup>. Organisation and political interest refer to the above-mentioned distinction discussed by Baroni et al.: organisation relates to that interest groups are an organised form of political behaviour, and interest groups have the political interest to influence policy outcomes<sup>[7]</sup>. Furthermore, informality indicates how interest groups engage in informal interactions with politicians in an attempt to

influence policy outcomes<sup>[10]</sup>. In sum, an interest group can be defined as an organisation that aims to influence or change policy outcomes by taking part in informal interactions with relevant policymakers.

### 2.2.3. SMO, interest group or patient organisation?

These organisations all have in common that they aim to induce change, but what are the differences? The differences between an SMO and a patient organisation lie mostly in what it prioritises as its main activity. For patient organisations, the main activity is to provide patients and their families with information and support<sup>[93]</sup>, which is something that SMOs do not do. SMOs focus on convincing those outside of the constituency of their grievances and the need for change<sup>[144]</sup>. While both patient organisations and SMOs use informal means to seek change, patient organisations tend to focus on establishing relationships with relevant actors such as medical professionals<sup>[84]</sup>, while SMOs organise demonstrations or start petitions<sup>[70]</sup>. Most patient organisations emphasize one specific disease or disability<sup>[73]</sup>, while SMOs usually draw their constituency from the larger social movement they are part of<sup>[25]</sup>.

Based on the literature, four main differences between SMOs and interest groups can be distinguished. First, according to Snow, Soule and Kriesi, SMOs are active in the political arena but their activity usually expands beyond this and into other institutional areas, while interest groups focus on the government, and are active in the political arena<sup>[103]</sup>. Secondly, interest groups generally use informal interactions in the political arena to reach their goals and interests, while SMOs operate outside of the political arena, and use informal means like demonstrations<sup>[103]</sup>. Third, interest groups are not dependent upon their constituents to take action, while SMOs are dependent upon their constituents and they have to mobilise them<sup>[25, 103]</sup>. Lastly, according to Csáir, SMOs are always part of a larger network of organisations and groups and are a part of a broader social movement, while interest groups can be independent and operate in isolation from other organisations<sup>[25]</sup>.

The difference between patient organisations and interest groups lies in that patient organisations focus and rely on the relationship between and with their members<sup>[93]</sup>, while interest groups do not need a constituency to do their work<sup>[25]</sup>. Furthermore, interest groups only focus on influencing the government<sup>[103]</sup>, while, although patient organisations can try to influence political decision-making processes, they also engage with other actors, like health care providers<sup>[84]</sup>.

SMOs, patient organisations and interest groups can have similar goals and objectives and choose to work together. This can develop into what Ruzza defines as a social movement coalition<sup>[95]</sup>, wherein SMOs, patient organisations and interest groups organise themselves and work together on the same goals in an attempt to influence policies. This also gives the benefit of gaining access to various resources that were first not available to all organisations. These coalitions can take the form of formal, durable and

- 7 McCarthy & Zald (1973), as cited in McCarthy, J. D. (2013, p. 1). Social Movement Organization (SMO). In D. A. Snow, D. Della Porta, B. Klandermans, & D. McAdam (Eds.), *The Wiley-Blackwell Encyclopedia of Social and Political Movements*. Blackwell Publishing Ltd. <https://doi.org/10.1002/9780470674871.wbespm195>
- 8 Jordan, as cited in Baroni, L., Carroll, B. J., Chalmers, A. W., María Muñoz Marquez, L., & Rasmussen, A. (2014, p. 144). Defining and classifying interest groups. *Interest Groups & Advocacy*, 3(2), 141–159. <https://doi.org/10.1057/iga.2014.9>
- 9 Bentley, as cited in Baroni, L., Carroll, B. J., Chalmers, A. W., María Muñoz Marquez, L., & Rasmussen, A. (2014, p. 144). Defining and classifying interest groups. *Interest Groups & Advocacy*, 3(2), 141–159. <https://doi.org/10.1057/iga.2014.9>

professionally organised collaborations, or they can have a more temporal character[95].

### 2.3. The media and social movements

In this part, the relationship between social movements and the media will be elaborated upon. To find an answer to the research question, it is important to determine under which circumstances a social movement can influence discourses in the media. Therefore, it will first be explained what discourses are. What follows is an elaboration on why social movements use the media. Third, the problem of asymmetrical dependency and possible ways to overcome this problem is explained. Lastly, it will be demonstrated how the influence of social movements on discourses in the media can be determined.

#### 2.3.1. Discourses

A discourse is a way to make meaning of the world around us[51]. Discourses can be seen as the collections of ideas, concepts or categories we use to give meaning to certain phenomena[57]. Discourses are (re)produced through social practices[130], as well as that discourses are social practices. Discourses construct and are constructed by concepts, institutions and events[51]. This is mainly done through communication in text or talk, but also through images or body language[130]. Thus through discourse, we communicate our particular understanding of the world[57].

#### 2.3.2. Reasons to use the media

The main goal of social movements is to generate social and/or political change, for which they have to reach the political agenda. To do so, social movements aim to influence the public discourse to affect the political agenda. A way to have an impact on the public discourse is to influence the discourses in the media[4] because media discourse is a type of public discourse, which can be read and seen by everyone[83]. The literature identifies three main reasons why social movements use the media, in an attempt to influence the public discourse.

The first reason is mobilisation. Social movements try to reach their constituency to either mobilise them or bring a message across by using the media as a platform[54]. Second, social movements need the media for validation because when the social movement gets attention from the media, it means it is being acknowledged as a relevant player[53, 54]. The third purpose is to broaden the scope of the issue at stake, for example by drawing third parties into the conflict, either as supporters or as an opposing party[54].

Why do social movements try to influence the public discourse if they want to reach the political agenda? The relationship between discourses in the media and decision-making processes are mediated by the public opinion. The opinions of individual voters are relevant for policymakers because it partially influences their decisions[52]. Research by McCombs and Shaw and McCombs et al. demonstrated that the media influences both *what* topics are talked about (first-level agenda-setting), as well as *how* people talk about these topics (second-level agenda-setting)[71, 72]. McCombs et al. found that the media tend to frame issues in a certain way, to make them seem more or less important and thereby influence how people think about these issues[71]. Social movements thus want to influence the public discourse because it can affect the public opinion, which affects the political agenda. Therefore, social movements do not only need to attract attention, but they also need to be able to have a say about how issues are discussed. In this

way, a social movement can influence public discourse. However, this raises the question of how social movements can attract media attention in the first place?

#### 2.3.3. The struggle of asymmetrical dependency

Social movements are relevant for the media because they provide the media with content, for example when there is drama or conflict, that the media can print or broadcast[54]. The media have two different roles: on the one hand, they act as gatekeepers, and on the other hand, they are players. As gatekeepers, journalists decide who is a relevant and important actor, and they have a lot of influence over who is allowed to speak. As players, they participate in the framing of certain events or issues by giving a certain meaning to them[52, 53].

The problem is that social movements struggle to generate media attention because social movements need the media much more than the media needs them. This is called asymmetrical dependency[19, 54]. As a result, social movements have to fight to get access to the media, to be mentioned in news articles and to become a validated player. To ensure media coverage, social movements rely heavily on resources such as money, networks and solidarity. And not only do they have to struggle to get access to the media, but they also struggle to get there before other SMOs within their coalition or other social movements with opposing values[54].

Scholars argue that there are a few aspects that can increase the chances of a social movement organisation getting media attention, and thereby work around the issue of asymmetrical dependency. According to Andrews and Caren, organisational resources are extremely important for SMOs[4]. By, for example, having a paid staff that maintains relationships with journalists, the organisation is more likely to generate attention once in a while. Gamson and Wolfsfeld argue that the more resources an organisation has, the more likely it will be that it can generate media attention[54]. Moreover, Gamson adds that a clear authority structure and strong control over staff members and volunteers is important to ensure that the media sees the SMO as a legitimate player[53].

Having expertise over a specific topic can also increase the likelihood of getting media attention[4] because in that case, the media needs the organisation for information when they want to discuss that specific topic. Furthermore, being a part of a broader social movement network or coalition can benefit an SMO. This can grant an SMO with resources, such as a larger network including different journalists, or being affiliated with an already more established and validated organisation[4]. Gamson and Wolfsfeld claim that this can also help social movements to divide the labour among various actors, which bring down the costs for each coalition partner while the preferred message is getting media attention[54].

#### 2.3.4. Visibility, standing and framing

How can we measure whether a social movement has been successful in attracting media attention, and is having an influence over what has been said or written? Scholars tend to look at three aspects to determine this. At first, an organisation must become visible. Because media attention is scarce, simply being mentioned is already a significant step to become an actor in the public discourse. Resources can increase the likelihood that a social movement can attract media attention[4]. Social movements that

have been around for a longer time are more likely to have been able to invest in resources, like time and money in network ties and relationships with journalists. Therefore, the first hypothesis is:

**H1. The longer the movement exists and the more developed it becomes, the more media attention it attracts.**

The second aspect is having standing with journalists. As mentioned before, having journalists in one's network is an important resource that increases the chances of generating media attention. According to Gamson, "standing means having a voice in the media."<sup>10</sup> In other words, standing means that an individual or a group is considered to be a relevant actor and is not only talked about, but involved in the discussion. According to Ferree et al., having standing implies that a social movement is not merely an object being discussed, but seen as a relevant actor with a voice<sup>[52]</sup>.

Following the theory of second-level agenda-setting, the media can influence how an audience thinks about a certain topic. Therefore, it is in the interest of the social movement to be able to influence how an audience perceives a certain topic. Therefore, 'having standing' with journalists gives social movements more power because they are perceived as a legitimate source, which enables a social movement "to provide interpretation and meaning"<sup>11</sup> to events or objects in which the movement is involved<sup>[142]</sup>. In practical terms, it means that an individual or organisation of the movement has been directly or indirectly quoted in the media<sup>[142]</sup>. If that is the case, the social movement is more likely to influence the public discourse. As mentioned before, the longer a social movement has been around, the more likely they have been able to establish relationships with journalists. Therefore, the second hypothesis is:

**H2: The longer the movement exists and the more developed it becomes, the more standing with the media it can generate.**

A third important way in which social movements can influence public discourse is by framing. According to Goffman, frames help individuals interpret things in their lives and the world by being able to identify and label them.<sup>12</sup> By framing a certain topic or event, it can become clear what is important about that topic or event, and what is less important. A frame is used to help us understand and place issues in broader social and political contexts. This is done by using certain words, pictures, symbols and arguments to demonstrate what this topic or event means<sup>[53]</sup>.

Benford and Snow argue that social movements actively engage in the process of framing and try to generate frames that help the goal of seeking or resisting change<sup>[8]</sup>. Again following the theory of second-level agenda-setting, the media can influence how an audience thinks about a certain topic, therefore a social movement needs to frame an event, problem or issue to ensure that the audience perceives it in a certain way that benefits their goal. Whenever a social movement has been able to ensure that its preferred frame gets media coverage, it can be considered successful and as having an impact on the public discourse. A movement is more likely to influence the framing in the media when it has been able to become standing with the media. Therefore, the third hypothesis is:

**H3. Whenever a social movement has been able to generate standing with the media, the more likely it can influence the framing.**

Thus if a social movement generates media attention, attracts standing and can influence the framing, the movement can successfully influence the public discourse<sup>[52]</sup>.

10 Gamson, W. A. (2004, p. 251). Bystanders, Public Opinion, and the Media. In D. A. Snow, S. A. Soule, & H. Kriesi (Eds.), *The Blackwell Companion to Social Movements* (pp. 242–261). Blackwell Publishing Ltd. <https://doi.org/10.1002/9780470999103.ch11>

11 Ferree et al., as cited in Wonneberger, A., & Jacobs, S. (2017, p. 356). Media positioning: Comparing organizations' standing in the news. *Corporate Communications*, 22(3), 354–368. <https://doi.org/10.1108/CCIJ-11-2016-0075>

12 Goffman, as cited in Benford, R. D., & Snow, D. A. (2000). Framing Processes and Social Movements: An Overview and Assessment. *Annual Review of Sociology*, 26, 611–639.



### 3. Methodology

In this chapter, firstly the research design will be explained. Second, how the data has been collected will be elaborated upon. Third, it will be discussed how the data is analysed. Lastly, the strengths and weaknesses of this research will be described.

#### 3.1. Research Design

To answer the main question, the extent to which the Dutch intersex movement influences the discourses in the Dutch media, a longitudinal case study research design will be used. A case study is “an intensive study of a single case or small number of cases which draws on observational data and promises to shed light on a larger popular of cases.”<sup>13</sup>. The case within this research is the media influence by the Dutch intersex movement. This case is used to study the influence of social movements on the public discourse in the media. The unit of analysis refers to what the researcher wants to draw the conclusions about, which is the amount of media influence by the intersex movement in the Netherlands; while the unit of observation refers to what is being studied, which are Dutch newspaper articles.

The independent variables (X) in this research are the amount of visibility, standing and framing, while the dependent variable (Y) is the discourses about intersex in the Dutch media. This case study has a longitudinal design, meaning that the independent variable (X) changes, while the dependent variable (Y) is being observed. This research design aims to approximate a causal relationship between X and Y but also looks at whether the changing background factors, like the number of intersex organisations in the Netherlands, influence this relation. By using a longitudinal design, it enhances the possibility of drawing causal inferences because it enables the researcher to better determine which mechanisms were responsible for certain outcomes or changes<sup>[56]</sup>. With the establishment of multiple (intersex) organisations in the Netherlands since 1990, the researcher can evaluate whether this influences Y through X.

#### 3.2. Research method

The main research question has been divided into two sub-questions. The first sub-question is: *When did the intersex movement emerge in the Netherlands and how did it develop?* This question will be investigated by doing desk research, which aims to provide an overview of the intersex movement in the Netherlands. The second sub-question is: *What discourses do Dutch newspapers construct surrounding intersex?* To answer this sub-question, a CDA will be conducted. Below, it will be explained how the data for the first sub-question was collected, second, it will be discussed what a CDA entails, and third, how the data for the second-sub question was collected will be demonstrated.

##### 3.2.1. Data collection first sub-question

To answer the first sub-question, data was collected to provide a systemic overview of the intersex movement in the Netherlands. Secondary sources, such as the websites of organisations, were collected during desk research by searching online. A ‘snowball search method’ was used, which can be compared to snowball sampling<sup>[59]</sup> the starting point of the data collection was the

website of NNID, which provided an overview of organisations in the Netherlands that are related to intersex and intersex issues. If one of these organisations mentioned another organisation on their website, this organisation was assessed to determine if it is part of the intersex movement i.e. if the organisation or group seeks change for intersex people. In addition, academic literature on the beginning of the intersex social movement was used to imbed the Dutch intersex movement in the broader context of the emergence of intersex activism, and further explain the origin of the two opposing frames. The answer to the first sub-question is discussed in Chapter 4.

##### 3.2.2. Critical discourse analysis (CDA)

As explained in the theoretical framework, discourses are a way to make meaning of the world around us. Discourse analysis entails the study of these discourses. One specific form of discourse analysis is CDA. CDA emphasises the role of power in the construction of discourses<sup>[129]</sup>. Discourses produce and reproduce dominance: who is in power and who can exercise that power<sup>[130]</sup>. CDA focuses on the seemingly neutral and normal strategies that are used to exert control and tries to understand how these strategies (re)produce structures of power. Power also relates to ‘access’: certain communicators have more or less access to certain contexts. For example, journalists have a lot of power by writing articles or making television reports because they control who gets to talk, what they talk about, and how it is being presented. Journalists, therefore, hold a specific kind of power: they can control media discourses<sup>[129]</sup>.

The main difference between discourse analysis and CDA is that the latter chooses the side of the dominated or oppressed group<sup>[129]</sup>. Critical discourse analysts use CDA as a means to critique those who are in power and have power over discourses, and thereby (re)produce structures of inequality that arise out of those power structures. This does not mean that CDA is biased, it still uses a systematic and analytical research method<sup>[51, 129]</sup>, which will be explained further below.

##### 3.2.3. Data collection second sub-question

The CDA in this research looks at what discourses are constructed in the media regarding intersex. The texts used to study the discourse are newspaper articles. Newspaper articles were chosen because they are easily available, public to everyone, and play a large role in producing the public discourse<sup>[83]</sup>. The newspaper articles were downloaded from the LexisNexis database. Therefore, a word list was made to find articles. The words in this list were included because they were previously used to describe intersex, such as ‘*interseksualiteit*’ or ‘*hermafrodit*’<sup>14</sup>, or because they are common words to describe intersex in Dutch now, such as ‘*intersekse*’ or ‘*DSD*’. Lastly, the words used to describe different variations of intersex were included, such as ‘*Klinefelter Syndroom*’.

13 Gerring, J. (2017, p. 28). Case Study Research. Principles and Practices (2nd Editio). Cambridge University Press.

14 The terms ‘intersexuality’ and ‘hermaphrodite’ is no longer used because those terms are considered offensive<sup>[134]</sup>.

| Search word  | Number of results<br>(before attribute coding) |
|--|--|
| Intersekse   | 152  |
| Interseksuelen                                       | 56   |
| Seksediversiteit                                     | 18   |
| DSD/intersekse OF intersekse/DSD                     | 11   |
| Disorders of Sex Development                         | 4  |
| Hermafrodit  | 285  |
| Hermafroditisme                                      | 10   |
| Echt Hermafroditisme                                 | 0  |
| Mannelijk pseudo-hermafroditisme                     | 0  |
| Vrouwelijk pseudo-hermafroditisme                    | 0  |
| Pseudo-hermafroditisme                               | 1  |
| Hypospadie   | 27   |
| Interseksualiteit                                    | 35   |
| Androgeen Ongevoeligheid Syndroom OF AOS             | 5  |
| Compleet Androgeen Ongevoeligheid Syndroom           | 0  |
| Partieel Androgeen Ongevoeligheid Syndroom           | 0  |
| Morris-syndroom                                      | 0  |
| Adrenogenitaalsyndroom OF Androgenitaal syndroom     | 22   |
| Anti-Müller-Hormoon                                  | 3  |
| Conditions Affecting Reproductive Development (CARD) | 0  |
| Gonadale dysgenesie                                  | 0  |
| Syndroom van Swyer                                   | 1  |
| Klinefelter Syndroom OF Syndroom van Klinefelter     | 6  |
| MRK-Syndroom OF MRKH-Syndroom                        | 5  |
| Turner Syndroom OF Syndroom van Turner               | 35   |
| The total number of articles: 676                    |  |

Table 3.1: Search word list

Based on the limited time and a large amount of data, it was not possible to include every Dutch newspaper. Therefore, the search was narrowed down to six newspapers. These newspapers were selected because they have the biggest reach<sup>15</sup> in the Netherlands and because they present a variety of different political and social perspectives: *De Telegraaf*, *Trouw*, *de Volkskrant*, *AD/Algemeen Dagblad*, *NRC Handelsblad*, *Het Parool*.<sup>16</sup> The newspapers vary from a more popular, right-wing style (*De Telegraaf*, *AD/Algemeen Dagblad*)[6] to a qualitative style, including a left-wing (*de Volkskrant*, *Het Parool*)[7], a liberal-conservative (*NRC Handelsblad*)[6], and a religious-philosophical orientation (*Trouw*)[114].

The data collected spans a period from the 4th of November 1991 until the 7th of February 2021. This has two reasons. First, LexisNexis has archived newspaper articles since 1991.<sup>18</sup> Second, before 1990 there is no indication of an intersex movement in the Netherlands because the first organisations of the intersex movement were established in 1990 (see Chapter 4) which is why 1991 is a good starting point of our timeline. The data collection resulted in 676 articles. Eventually, for the analysis, the 2021 articles were excluded because it is not possible to draw conclusions about the discourse in 2021 based on little more than two months of data.

### 3.3. Data analysis

As explained in the theoretical framework, three criteria are relevant to examine whether a social movement has been successful in influencing the public discourse. First, does the intersex movement receive media coverage? Second, does the movement have standing? Third, which frames does the media use?

#### 3.3.1. Visibility, standing and framing

The first criterion, the visibility of the intersex movement, will be quantified by giving an overview of the number of articles published each year. This will answer the question of whether the intersex movement has been able to gain more media attention over time. The second criterion, standing, will be analysed based on whether or not an actor has been quoted. A quote can be direct: 'Lisa said: "I like cats"'; or indirect: 'Lisa said that she likes cats'. Although both count as standing, an indirect quote could have been altered by the journalist to fit in the text, which might take away the specific meaning of what an actor has said. Therefore, a direct quote is considered to have more influence on the framing than an indirect quote.

The third criterion refers to the framing within the news article. Intersex can be perceived from two different frames: a medical frame and a human rights frame. As already mentioned in the introduction, these frames have different perspectives on sex and gender. These frames think differently about the medical treatment of intersex people, the LGBTI community and from which perspective intersex should be studied. Table 3.1 provides an overview of the different standpoints of both frames, which is based on academic literature and the website of NNID.

15 The newspapers have a reach of: *AD/Algemeen Dagblad* 1.130.000; *De Telegraaf* 1.026.000; *De Volkskrant* 627.000; *NRC Handelsblad* 416.000; *Trouw* 282.000; *Het Parool* 70.000. Source: Stichting NOM (2021).

16 *Het Parool* was not selected for its reach, but for its left-wing orientation to balance out the two right-wing newspapers.

17 These classifications are made in general by Bakker and Vasteman (2007), and do not specifically refer to the newspaper's perspective on sex and gender or LGBTI issues.

18 In LexisNexis the archives of the different newspapers are available as follows: *De Telegraaf* January 2, 1999; *Trouw* January 2, 1992; *De Volkskrant* June 11, 1994; *Het AD/Algemeen Dagblad* November 4, 1991; *NRC Handelsblad* January 8, 1990; *Het Parool* July 1, 1992.

| The medical frame   | The human rights frame  |
|---|---|
| Only uses the term 'Disorders of Sex Development' (DSD), and sometimes "Differences" (instead of disorder).                 | Only uses the word 'intersex', rejects the term DSD.  |
| Research from a medical perspective (intersex is seen as a medical issue)   | Research from a social scientific perspective (sees the views and perspectives of society as the issue)   |
| Sees sex as binary: human bodies should look like the normative standards that have been set up for male and female bodies. | Sees sex as a spectrum: human bodies come in an endless amount of different variations and do not have to look like the normative standards that have been made for men and women.  |
| Considers medical treatment as a standard intervention for intersex people.   | Strongly against non-consensual, medically unnecessary treatments, which are medical treatments where proxy consent is given (by e.g. parents of a child), but that can be postponed, without endangering the life of the person, until informed consent can be given by the person (e.g. when the person is old enough to do so). This frame is thus not against medical treatments that cannot be postponed because the situation is life-threatening, and not against treatment that is based on informed consent. |
| Focuses on the medical treatment of intersex people and strives to improve the medical treatment for intersex individuals   | Advocates for and defends the rights of intersex people, emphasises the bodily autonomy, integrity and right to make decisions of intersex people and children  |
| Argues that parents can make choices for their children   | Argues that parents should not make choices for their intersex children   |
| Rejects the term 'intersex' and the idea that intersex can be a part of the LGBTI community                                 | Argues that intersex people can call themselves however they want to and can choose themselves whether they want to be part of the LGBTI community  |
| Focuses on hospitals, patients and denies the diversity of sex  | Focuses on society, individual experiences and the diversity of sex   |
| Wants intersex to continue to be medicalised  | Wants to demedicalise intersex  |

Table 3.2: the two frames regarding intersex[24, 38, 41, 63, 88, 99, 126].

### 3.3.2. Coding

The coding scheme for this research is largely based upon an article by Reynolds (2019), who uses qualitative coding to enhance the systematic and empirical manner in which CDA is conducted. Coding is the method to depict the meaning of written text, by applying specific attributes to certain words or phrases that compile the discourse[92]. Reynolds argues that it is important to have a specific coding method, which not only describes what is coded but also how it is coded[92]. As qualitative research, and specifically, discourse analysis can be prone to personal bias of the researcher, it is of great importance for the reliability and transparency of the research that is clear what steps have been taken to code the data[55]. According to Gerring, the more transparent a researcher is about the design, methods and steps, the more likely research can be replicated, which enhances the internal validity[55].

The coding of the data happens in two cycles. Reynolds's coding scheme does not only include thematic coding, but also longitudinal coding, which is an important part of this research. Since the two frames that will be coded for have already been established, a few steps can be skipped wherein researchers

normally establish frames while they are coding the texts. The first part, the so-called first-cycle, includes the following steps:

Attribute coding: this first step pre-codes the data and notes the descriptive aspects of the data systematically in a code sheet in Excel. This includes information such as the title, the newspaper, the date, the general theme and the writer of the article. Moreover, in the program ATLAS.ti the year was coded to ensure that in the second-cycle, the articles could be analysed in chronological order.

During attribute coding, more than a hundred articles were removed from the data set as they were not relevant for the research. For example, some articles that were included based on the word 'hermafrodit' only discussed animals that are hermaphrodite. Since this research focuses on social movements and the experiences of people in the social world, it would not be logical to include articles about animals. These articles do not tell anything about how intersex people and intersex issues are perceived and framed unless the article refers to both animals and people (e.g. comparing animals and humans). Therefore, these articles were excluded, which resulted in a data set of 511 articles.<sup>19</sup>

Holistic coding/descriptive coding: during this round of coding, the articles will be coded based on which frame or frames can be

19 The complete data set is in the possession of NNID and can be requested at any time.



identified in the article in general, who is directly and indirectly quoted, and which frame the actors, who are quoted, use. The program ATLAS.ti is used for this round of coding.

After the first-cycle analysis, the analysis continues to the second-cycle analysis. In this part, the articles will be read again in chronological order. In this way, discourses over time become visible, as well as at what point in time actors are being quoted. Longitudinal coding enables the researcher to look at how the presence and use of these frames have developed over time[92]. Moreover, value/versus coding will be included in this step because the focus will be on whose perspective or opinion is being validated, which frame is being more acknowledged and which actors are in conflict with each other[92].

### 3.3.3. Exclusion and silencing

Two important notes need to be made here. First of all, CDA does not only look at who is speaking but also who is *not* speaking i.e. who has *not* been invited to say something? Some people, and in this context specifically journalists, hold the power over whom they ask to interview about intersex, and more importantly: who is *not* asked. As argued by Van Dijk, “such modes of exclusion are also apparent in discourse structures themselves.”<sup>20</sup>. This exclusion demonstrates who receives less attention in the media and is thus less powerful. This kind of exclusion can also be evident whenever two social groups are allowed to say something, but one group has more power than the other. This can result in certain groups being implicitly or explicitly restrained in what they can say, and what is written down. During the analysis, the researcher has continuously reflected on the possibility that certain groups or individuals are being excluded, and what implications this can have on the discourse.

Second of all, discourses broadly do two things: either they reproduce an already existing discourse or they transform an

existing discourse[51]. The sex and gender binary system has been a dominant discourse for a long time, and continues to be reproduced in many aspects of our lives (e.g. sex registration in official governmental documents, male or female bathrooms). When alternatives to this binary system are not recognised, the dominant discourse seems the only ‘natural’ option. According to Wodak, whenever the dominant discourse is not actively challenged, it reproduces the dominant discourse[141]. This research follows the conceptualisation of ‘silence’ as a discourse, formulated by Macalpine and Marsch: by not talking about certain things or not challenging specific discourses, the dominant discourse is constructed as ‘normal’[68]. Therefore, during the analysis, articles that do not explicitly speak out against, for example, non-consensual medically unnecessary surgeries, or do not mention ‘intersex’ as a suitable term, are considered to reproduce the dominant frame, which is the medical frame.

### 3.4. Internal validity

The internal validity of a case study pertains to the extent to which the researcher can draw conclusions about the relationship between the independent and dependent variable[55], i.e. does the intersex movement influence public discourse? The problem of causality is that it is difficult “to establish a causal link between a given movement and an observed change”<sup>21</sup>. Can we be entirely sure that the observed change is not caused by another factor? There are a few ways in which the internal validity can be improved. One way is by looking at processes over time, this will give a higher probability that the researcher can distinguish the various mechanisms at play. This is an important part of the research design. Secondly, Giugni argues that by specifying the types of consequences that are being studied (e.g. public discourses in the media) and finding relevant causes (e.g. visibility, standing and framing), the internal validity of the research is enhanced[56].

20 van Dijk, T. (1993, p. 260). Principles of critical discourse analysis. *Discourse & Society*, 4(2), 249–283.

21 Giugni, M. (1999, p. XXIV). How Social Movements Matter: Past Research, Present Problems, Future Developments. In M. Giugni, D. Mcadam, & C. Tilly (Eds.), *How Social Movements Matter* (pp. 3–21). University of Minnesota Press.

## 4. The intersex movement in the Netherlands

In this chapter, the answer to the first sub-question will be provided. To understand the rise and development of the intersex movement, this chapter will elaborate on the emergence of the medical and human rights frame. Second, it will be discussed which organisations for intersex people are established in the Netherlands, as well as the relations between them. Third, it will be argued why the intersex movement can be defined as a social movement. Lastly, the relation between LGBTI organisations and intersex organisations will be explained.

### 4.1. The emergence of the two frames

#### 4.1.1. Medicalisation

Intersex has been medicalised since the 1900s[41]. Medicalisation refers to “viewing a natural phenomenon in a medical framework where the medical view is seen as the authoritative, if not hegemonic, view”<sup>22</sup>. Medical authority is an important trait of our society[16] and is widely accepted[88]. This medical authority stems from the rise of the ‘scientisation’ of modern-day decision-making, which means that scientific research is used to decide what decisions should be made. Consequently, some social problems are made medical for doctors to be able to make rationally informed decisions[16].

This medicalisation forms the basis of the medical frame through which intersex is perceived. The medical frame views intersex as a condition or deviance that needs to be fixed or corrected[80, 88, 89] because intersex bodies do not fit the norm for ‘normal’ human bodies[88]. As a result, medical standards and practices were installed to ensure that intersex bodies could be altered to conform to a normative standard. This normative standard stems from the idea that a person’s sex and gender must align with each other and fit in one of two categories: male or female[17, 18].

The medical frame became dominant in the 1950s due to the theories of John Money[38]. Money argued that children were born psychosexually neutral, which means that children are born without a gender identity, but that this develops while they grow up. Money argued that genitals were the most important sign for children to start acting according to their gender. When intersex children had, for example, ambiguous genitalia, this meant that they had to receive corrective surgery right after birth. This was to ensure that their genitals resembled the normative standard for male or female genitalia and that they would develop a ‘normal’ gender identity that was the same as their sex[38, 41, 88]. Moreover, Money’s theory involved a secrecy protocol that was deemed necessary to not disturb the child’s gender development. This meant that either parents were never told that their child was intersex or parents were told to never tell their child that they were intersex[38, 88].

#### 4.1.2. Intersex Society of North America

Before the 1990s, there were some organisations and groups that were formed around specific intersex variations[20], such as patient organisations for girls and women with Turner syndrome in the

US[119], or a support group for girls and women with Androgen Insensitivity Syndrome (AIS) in the United Kingdom[2]. However, during the 1990s, the medical frame through which intersex was perceived became challenged by intersex activists. The first politicised intersex organisation, the Intersex Society of North America (ISNA), was founded in 1993 by Cheryl Chase. The organisation challenged the medical consensus about intersex and perceived intersex from a human rights frame[20, 38, 88]. Chase did not view intersex as a disease, rather she disputed the heteronormative assumptions and the binary system that, according to her, caused “the violence directed at our bodies”<sup>23</sup>. The organisation opposed non-consensual and medically unnecessary surgeries<sup>24</sup> on intersex children, as well as the secrecy protocol[20, 38, 41, 88].

Other aims of ISNA was to provide a platform through which intersex people could support each other, as well as providing information about, for example, patient autonomy, besides medical information[41, 88]. The organisation also wanted to make intersex more visible in society, so they spread stories of intersex people through a newsletter called ‘Hermaphrodites with Attitude’[20, 89]. The organisation received support from transgender activists, and later also from gay and lesbian organisations, and they started to work together on common issues. In the 1990s, the similarities between intersex and LGBT organisations could be found in the medicalisation of those identities.<sup>25</sup> LGBT individuals recognised the struggle against a dominant medical frame that was meant to socially control people’s bodies and identities[20].

ISNA was able to draw attention to two issues that intersex people had to deal with. First, there has been no research into the outcomes of the medical treatment of intersex people, which meant that medical professionals had no idea what the long-term consequences were of procedures and surgeries[38]. Later research demonstrated that some intersex individuals were unhappy about the surgeries they underwent. Some of them faced physical and psychological problems, such as feeling isolated, alienated and freakish[24, 38]. Second, the secrecy protocol caused psychological issues for intersex people. Many did not know what had happened to them[38, 89], others were told that intersex was something to be ashamed of and that they should not tell anyone about it[89]. This caused many to feel isolated and insecure[38, 89].

#### 4.1.3. Disorders of Sex Development (DSD)

In 2006, a group of medical professionals decided that the terminology surrounding intersex had received a negative connotation[63] because the word ‘intersex’ implicated that people were between (‘inter’) male and female (‘sex’), while most intersex individuals identify as either male or female[134]. After a clinical consensus meeting in 2005, the term Disorders of Sex Development (DSD) was proposed: “congenital conditions in which development

22 Preves, S. (2001, p. 532). Sexing the Intersex: An Analysis of Sociocultural Responses to Intersexuality. *Journal of Women in Culture and Society*, 27(2), 523–556.

23 Chase, C. (2006, p. 307). Hermaphrodites with Attitude. In S. Stryker & S. Whittle (Eds.), *The Transgender Studies Reader* (pp. 300–314). Routledge. [https://readthenothing.files.wordpress.com/2010/10/hermaphrodites\\_with\\_attitude1.pdf](https://readthenothing.files.wordpress.com/2010/10/hermaphrodites_with_attitude1.pdf)

24 The OHCHR (n.d.) defines medically unnecessary surgeries as treatments that are only done to ensure that a child has a body that fits with the normative expectations of what a male or female body should look like.

25 For example, being homosexual was considered a disease by the World Health Organisation until 1990[143].

of chromosomal, gonadal or anatomical sex is atypical"<sup>26</sup>. The new terminology was meant to create a consistent and clear framework for doctors, patients and other people involved[63].

The fact that at the consensus meeting about 50 clinicians and only two representatives of the intersex community were present[18], can be seen as both a cause as well as a consequence of the two camps. According to Carpenter, one of the two representatives said that their presence was merely needed to validate the new terminology rather than that their input was deemed necessary[18]. At this point, the medical and human rights frames were already colliding with each other, which caused the underrepresentation of intersex individuals at the meeting. Additionally, the meeting caused the two sides to drift even further apart. Intersex activists found the term 'disorder' much more stigmatising than the previous term 'intersex'[24, 28] because it implies that intersex is a 'malformation' that can be 'fixed'[18], and consequently, intersex activists continued to use the term 'intersex'[24, 134].

DSD was nevertheless adopted by most medical professionals and patient advocacy organisations. Over time, some medical professionals and patient organisations have changed the term 'disorder' to 'differences'[24, 76], to move away from the idea that intersex is something 'wrong' and that it can be 'fixed'. Davis argues that the DSD terminology is mainly used by "medical professionals to reassert their authority and reclaim jurisdiction over intersexuality in light of intersex activism"<sup>27</sup>. By naming and framing intersex as a disorder, medical professionals organised human bodies in 'normal' and 'not normal' and reproduced the binary sex system of male and female[28].

On the contrary, intersex organisations and activists argue that bodily variation is simply an expression of human diversity and not something that should be seen as a 'disorder'[76]. They perceive intersex through the human rights frame that holds that not only gender is a social construct, i.e. the characteristics we have assigned to male and female gender roles, but also sex is a social construct, i.e. the characteristics we have assigned to male and female bodies. Intersex bodies do not fit the social construction of sex, and intersex activists argue that this does not make it a 'deviation', rather intersex is a "natural variation"<sup>28</sup>.

Instead of only emphasising the bodily characteristics that determine if someone is intersex, intersex organisations emphasise the social and human experiences of intersex. This includes for example the stigmatisation and discrimination intersex people face, due to being intersex. From a human rights perspective, intersex is defined as "the lived experiences of people who are born with a body that does not meet the normative definition of male and female"<sup>29</sup>.

## 4.2. Intersex in the Netherlands

Since the 1990s, there are some organisations in the Netherlands that are aimed at providing support for people with specific

intersex variations, such as Klinefelter syndrome or Turner syndrome. In the 2010s, an organisation with a more politicised view was established which started to challenge the medicalised perspective on intersex. In the following section, an overview of Dutch organisations for intersex people will be presented.

### 4.2.1. Organisations in the Netherlands

The first organisation for intersex individuals was the *Nederlandse Klinefelter Vereniging*, which was founded in 1990[145]. Klinefelter syndrome is an intersex variation that only occurs with men, whereby besides having one Y-chromosome there are multiple X-chromosomes. This causes a variety of different symptoms that differ per person, such as having relatively thin arms and legs, a small penis, small testes, and reduced fertility[78].

The *Nederlandse Klinefelter Vereniging* advocates for the rights and interests of men with Klinefelter syndrome. Their primary goal is to improve the well-being of men with Klinefelter syndrome and their families. Their other goals are: providing contact between members, giving information through their website, member-magazine etc., and advocating for better health care services for people with Klinefelter syndrome. An important aspect of their mission is to help men with Klinefelter become more accepted in society, and to accept themselves[77].

In 1987, the organisation *Bijnierverseniging-NVACP*<sup>30</sup> was founded for people who have an adrenal gland disease. Since 1999, this organisation includes people who have the intersex variation Congenital Adrenal Hyperplasia (CAH)[11, 13]. CAH causes the adrenal gland to not produce the right amount of hormones that are responsible for controlling the amount of salt in the body. If their salt level is not corrected with medication, it can become fatal[65]. CAH can occur with boys and girls, but for girls, the overproduction of androgen (the 'male' hormone) can cause the external genitalia to 'masculinise'[97, 120].

The organisation aims to bring people with an adrenal condition into contact with each other, provide them with information and advocate for their interests[12]. They maintain a close relationship with medical professionals and researchers[14] and have an advisory team of medical professionals and health care workers, that answers questions of members[15]. Furthermore, the organisation wants to raise awareness about adrenal conditions by attracting media coverage[14].

In 1999, the organisation *Turner Contact Nederland*[118] and the organisation *Stichting MRK-Vrouwen*[104] were founded. *Turner Contact Nederland* is an organisation for women with Turner syndrome, whereby the X-chromosomes are underdeveloped or there is only one X-chromosome[116]. The organisation aims to organise opportunities for members to come in contact with each other, to provide information for their members, and to defend the interests of women with Turner syndrome[117, 118].

26 Hughes, I. A., Houk, C., Ahmed, S. F., Lee, P. A., & Lawson Wilkins Pediatric Endocrine Society (LWPES)/European Society for Paediatric Endocrinology (ESPE) Consensus Group. (2006, p. 149). Consensus statement on management of intersex disorders. *Journal of Pediatric Urology*, 2, 148–162. <https://doi.org/10.1016/j.jpurol.2006.03.004>

27 Davis, G. (2011, p. 155–156). "DSD is a perfectly fine term": Reasserting medical authority through a shift in intersex terminology. In P. J. McGann & D. J. Hutson (Eds.), *Sociology of Diagnosis* (12th ed., pp. 155–182). Emerald Group Publishing Limited.

28 Naezer, M., Oerlemans, A., Hablous, G., Claahsen-Van Der Grinten, H., Van Der Vleuten, A., & Verhaak, C. (2021, p. 9). "We just want the best for this child": contestations of intersex/DSD and transgender healthcare interventions. *Journal of Gender Studies*. <https://doi.org/10.1080/09589236.2021.1881462>

29 NNID. (2018a, p. 10). Strategisch Plan 2018–2022. <https://nnid.nl/over-ons/anbi-status/>

30 Abbreviation stands for: Dutch Association for Addison and Cushing Patients

Women with Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome are born without a vagina and a uterus[105]. The organisation was founded by women who have MRKH-syndrome and aims to enhance awareness about MRKH-syndrome, provide support for women with MRKH-syndrome through talking groups and a forum, and ensure women have access to information about the syndrome[104, 106]. They have an advisory committee of medical professionals who are specialised in MRKH-syndrome, that answers medical-related questions[106].

Between 2000 and 2020, *Trefpunt Hypospadie* was a website where boys and men with hypospadias could find each other. Hypospadias means that the urethra does not end at the top of the penis but in the middle, or close to the scrotum[50]. Hypospadias can be a sign of an intersex variation, but this is not always the case[26]. In 2020, the founder decided to abolish *Trefpunt Hypospadie*, as according to him internet forums are no longer the obvious place to find information[113].

The organisation *AISNederland* was founded in 2001. The organisation was formerly led by Inge Intven and Miriam van der Have, whose main aim was to demedicalise intersex[125]. In addition, the organisation's purpose was to provide information about and support women with AIS[45]. People with AIS have XY-chromosomes, but the body is (partially) insensitive to androgen. This can lead to several things such as ambiguous genitalia, not having armpit hair, or the person's sweat having no scent[43]. Intven and Van der Have had conversations with medical professionals to try and discuss the problem of the medicalisation of intersex, but this proved to be difficult as not much research has been conducted into the issue, and they had to rely on their experiences which was not seen as legitimate by medical professionals[125].

*AISNederland* also actively tried to attract media attention, which resulted in an episode about AIS for the program *Vinger aan de Pols*[47], and some newspaper articles[44, 47]. After some years of trying to demedicalise intersex, Intven and Van der Have felt like their efforts were not paying off and they decided to stop being involved in the organisation[125].

*AISNederland* continued to exist and changed its name to *DSDNederland*[98]. Currently, the organisation defends the interests of all intersex individuals with a 46,XY sex variation.<sup>31</sup> *DSDNederland* still aims at creating contact opportunities between intersex people and taking away the taboo surrounding intersex by being open about it. The main aim of the organisations seems no longer to be to demedicalise intersex because the organisation works together with medical professionals to improve the diagnoses and treatment of intersex people[48], and has a medical advisory board that answers questions of members[46].

In 2004, the *Contactgroep Triple-X Syndroom* was established. Triple-X syndrome causes girls to have three X-chromosomes instead of two. Triple-X syndrome can cause, among other things, short term memory disorders, motoric disorders and speech problems[23]. *Contactgroep Triple-X Syndroom* was started by two mothers of

children with Triple-X syndrome, who tried to find more information about Triple-X syndrome. They created a website to share research articles. The group organises meetings days. They also maintain contact with medical professionals and researchers[121].

The above-mentioned organisations perceive intersex as a medical issue, which can be derived from their focus on medical information, health care and contact with medical professionals[77, 106, 118], as well as from their goals and activities (as described above). Moreover, *DSDNederland*, *Nederlandse Klinefelter Vereniging* and *Stichting MRK-Vrouwen* are members of the umbrella organisation *VSOP, Vereniging Samenwerkende Ouder- en Patiëntenorganisaties*<sup>32</sup> [138], which was founded to defend the rights of people with rare and genetic diseases[139]. The member organisations thus consider the specific intersex variation as a disease. Another aspect that shows the medical frame are the websites of the organisations. For example, *Bijnierverseniging-NVACP* refers to intersex variations by using terms like "congenital deviation"<sup>33</sup> [11], and *DSDNederland* uses "conditions"<sup>34</sup> [42], and only 'DSD' when describing intersex[44].

#### 4.2.2. NNID

When in 2013, the Dutch Ministry of Education, Culture and Science<sup>35</sup> called for research into intersex, Van der Have jumped on the bandwagon again and established a new organisation: *Stichting NNID*. The abbreviation 'NNID' initially stood for 'Nederlands Netwerk Intersekse/DSD'<sup>36</sup>. They included the term 'DSD' in the organisation's name as a political strategy, to ensure that the research that was being conducted used both intersex and DSD in their terminology[125]. Eventually, the research 'Living with intersex/DSD' was published[134]. Five years after the establishment, they changed the name to *Stichting NNID, Nederlandse organisatie voor seksediversiteit*<sup>37</sup> [125].

NNID was founded to further emancipate intersex individuals, make them more visible in society and advocate for their rights. NNID is the first Dutch intersex organisation that argues solely from a human rights perspective. The organisation actively engages in advocating intersex interests with the Dutch government[79]. The organisation is against non-consensual and unnecessary medical treatments of intersex children[126]. They argue that medical treatments should only be conducted when a person can give free and fully informed consent. This means that parents cannot decide for their children, and the government is responsible to protect children from these kinds of practices. They are not against medical treatments that are necessary for the health and well-being of the child[126]. Moreover, NNID has given input to the development of a quality standard<sup>38</sup> for DSD health care practices[60], because they argue that the human rights of intersex people should also be incorporated into the health care standard for intersex people (B. Keulen, personal communication, June 10, 2021). Their contribution included, for example, that the current psychological support should include a demedicalised perspective on intersex rather than only a medicalised perspective[60].

31 46,XY is the umbrella term for several sex variations including AIS[46].

32 In English: Association Collaborating Parent- and Patient organisations.

33 Translated from Dutch: "aangeboren afwijking"

34 Translated from Dutch: "aandoeningen"

35 Translated from Dutch: Ministerie van Onderwijs, Cultuur en Wetenschap

36 In English: Dutch Network Intersex/DSD

37 In English: Foundation NNID, Dutch organisation for sex diversity

38 The purpose of a quality standard is to describe what good quality care is, from the perspective of the person in need of care[60].

NNID has a Theory of Change that underlies its policy plan[81]. The Theory of Change is aimed at three different actors in society: the government, civil society and the intersex community[81]. Since this research focuses on public discourses in the media, the goals regarding civil society will be discussed. NNID wants intersex people to be able to participate in civil society without fear of discrimination or stigmatisation. Therefore, organisations, businesses and associations, that form the basis of civil society, have to be inclusive towards intersex people. To tackle discrimination, NNID deploys a strategy that focuses on signalling exclusion and discriminatory practices and putting it on the political agenda. NNID uses the media as a platform to directly or indirectly address civil society when practices are discriminatory towards intersex people. NNID holds that the media are an important means through which issues can be addressed, and social norms can be set[81].

### 4.3. Classifying the movement

There are a few important questions that still need to be answered: how do we classify these different organisations? How do these organisations relate to each other, in terms of goals and strategies? Do the above-mentioned organisations together form a social movement? Based on the theoretical framework, the different organisations will firstly be classified into patient organisations, interest groups or SMOs. Secondly, the relationships between these organisations will be elaborated upon and lastly, with the use of the definition of a social movement, as provided in the theoretical framework, it will be argued why the intersex movement in the Netherlands is a social movement. Table 4.1 gives an overview of organisations' activities.

#### 4.3.1. Classifying the organisations

In Chapter 2, a patient organisation has been defined as an organisation that wants to induce change with its main aim to improve the health care of its members and provide a support network. Based on this definition, the following organisations are patient organisations: *Turner Contact Nederland*, *Nederlandse Klinefelter Vereniging*, *DSDNederland*, *Bijniervereniging-NVACP* and *Stichting MRK-Vrouwen*.<sup>39</sup> These organisations organise contact opportunities for their members and try to build a collective identity among their members. To improve health care practices, the patient organisations *Bijniervereniging NVACP*, *de Nederlandse Klinefelter Vereniging*, *Stichting MRK-Vrouwen*, *Turner Contact Nederland* and *DSDNederland* have contributed to the development of a quality standard for DSD health care[60]. There are some small differences between the patient organisations. For example, only *DSDNederland* and *Bijniervereniging-NVACP* specifically mention having a media policy, while the other organisations do not.

As a type of SMO, patient organisations have to be organised to a certain extent to qualify as one, but *Contactgroep Triple-X Syndroom* is not formally organised because it does not have a board, statutes or a policy plan. Therefore, it cannot be classified as a patient organisation but rather as a patient support group. The group does not have the option to become a member and does not officially engage in advocating for the interests of people with Triple-X syndrome. Their main activities are providing information through their website and organising contact opportunities through contact days and a mailing list.

|                       |   |                          |                                |                                |             |      |                       |                          |
|-----------------------|---|--------------------------|--------------------------------|--------------------------------|-------------|------|-----------------------|--------------------------|
| Media policy          |   | ●                        |                                | ●                              |             | ●    |                       |                          |
| Improving health care | Improving the treatment of specific intersex variations | ●                        | ●                              | ●                              | ●           |      | ●                     | ●                        |
|                       | Improving the quality standard                          | ●                        |                                | ●                              | ●           | ●    | ●                     | ●                        |
| Providing information | About specific intersex variations                      | ●                        | ●                              | ●                              | ●           |      | ●                     | ●                        |
|                       | About intersex (rights) in general                      |                          |                                |                                |             | ●    |                       |                          |
| Interest / advocacy   | Defending interest of members                           | ●                        |                                | ●                              | ●           |      | ●                     | ●                        |
|                       | Lobbying/ defending interests of intersex people        |                          |                                |                                |             | ●    |                       |                          |
| Contact opportunities | Support groups  | ●                        | ●                              | ●                              | ●           |      | ●                     | ●                        |
|                       | Intersex community building                             |                          |                                |                                |             | ●    |                       |                          |
|                       |   | Bijnier vereniging NVACP | Contactgroep Triple-X Syndroom | Contactgroep Triple-X Syndroom | Nederlandse | NNID | Stichting MRK-vrouwen | Turner Contact Nederland |

Table 4.1: overview of the patient and intersex organisations activities.

Based on the definitions provided in the theoretical framework, NNID can be classified as both an interest group as well as an SMO. NNID is an interest group because the organisation tries to engage with policymakers in trying to induce change. Moreover, the organisation does not have any members, which means they are not dependent upon them to do their work. Organising contact opportunities between intersex individuals is not one of their main activities, although they do arrange activities from time to time that contributes to building an intersex community. For example, they organised an online World Intersex Pride in 2020[82]. Another important activity of NNID, which is characteristic of an SMO, is

<sup>39</sup> Due to the closure of the website of Trefpunt Hypospadias, it was not possible to find more information about this organisations which is why it will be excluded in the remainder of this chapter.



educating those outside of the constituency through the website 'www.seksediversiteit.nl'. In addition, NNID is part of a larger network of organisations and groups, which is more typical for an SMO than an interest group. NNID can thus be qualified as both an interest group and an SMO because it has characteristics of both. Table 4.1 demonstrates where NNID differs from patient organisations, while patient organisations main focus lies with a specific group of 'patients', NNID advocates for intersex issues in general.

#### 4.3.2. Classifying the intersex movement

Besides working individually, the organisations also work together with other organisations. Patient organisations work together with the previously mentioned VSOP, or with each other, or with NNID. For example, *Stichting MRK-Vrouwen* specifically states in their policy plan that they work together with *DSDNederland*, *Turner Contact Nederland* and NNID<sup>[106]</sup>. Furthermore, the organisations established an informal partnership 'DSD Together' between the *Nederlandse Klinefelter Vereniging*, *Turner Contact Nederland*, *DSDNederland*, *Bijniervereniging-NVACP*, *Stichting MRK-Vrouwen* and NNID. This collaboration between the organisations is not formally organised. A few years ago the group had a few meetings with the Ministry of Education, Culture and Science and Ministry of Public Health, Well-Being and Sports<sup>40</sup> in which ideas were exchanged about health care improvements and the position of intersex people in Dutch society<sup>[12, 31, 32]</sup>, but the group has not been together for a while now (B. Keulen, personal communication, June 10, 2021).

The intersex movement can be classified as a social movement because every organisation within the movement tries to induce change for intersex people and improve their lives and well-being, whether this is by improving their health care or medical treatment options, by participating in research or by advocating for the protection of intersex rights. The organisations try to challenge institutional structures, although NNID is more active in institutional settings than the patient organisations because NNID tries to influence political policy-making processes. Moreover, these organisations all work collectively rather than individually, and they tend to work outside institutional settings (i.e. not formally represented in parliament). Most of these organisations are formally organised by having a board, statutes and a policy plan (except *Contactgroep Triple-X Syndrome*), and they work together in various coalitions. These organisations all have been around for a period of time, which according to Snow indicates that they are not fly-by-nights<sup>[102]</sup>.

While the intersex movement has some goals and strategies in common, there are also some tensions within the movement that need to be addressed. As previously explained, patient organisations and NNID have different perspectives on intersex. Patient organisations view intersex as a medical issue, while NNID sees intersex as a social issue. However, these organisations do have similar goals, such as improving the lives of intersex individuals and making intersex more visible in society by being open about it and providing information. Whereas the patient organisations do this from a medical perspective, NNID does this from a human rights perspective. Sometimes NNID also engages in health care issues, such as contributing to the quality standards for DSD health care<sup>[60]</sup>, and sometimes patient organisations focus on the social experiences of intersex people, for example, the *Nederlandse*

*Klinefelter Vereniging* emphasises the importance of societal acceptance<sup>[77]</sup>.

#### 4.3.3. Intersex and LGBTI organisations

Another important actor for the movement is the LGBTI organisations. NNID has closely worked together with one LGBTI organisation and one organisation for transgender people: *COC Nederland* and *Transgender Netwerk Nederland* (TNN). The organisations find common ground in fighting against the heterosexual and sex- and gender-binary norms. *COC Nederland* is an organisation that defends the rights of LGBTI people in the Netherlands. The organisation was founded in 1946 by a group of homosexual men and focused on the emancipation of homosexuals, lesbians and bisexuals. Since 2012, the organisation officially advocates for the interests of transgender people, and since 2017, *COC Nederland* includes intersex people in their interest representation as well<sup>[22]</sup>.

TNN originated in 2008<sup>[111]</sup> out of different organisations for transgender people that decided a national organisation was necessary<sup>[109]</sup>. TNN defends the interests and rights of transgender people in the Netherlands. They provide policymakers and civil society organisations with information about transgender people. The organisation aims to empower transgender people in society by fighting discrimination against transgender individuals<sup>[110]</sup> and to ensure that transgender people can participate in civil society<sup>[112]</sup>.

*COC Nederland*, TNN and NNID have formed an alliance since 2017 based on the Theory of Change that was previously discussed. The organisations of the alliance each receive funding from the government. Since some experiences are shared between the various letters of LGBTI, the alliance is meant to further strengthen the mobilisation of the LGBTI community and work together on shared goals and interests. The organisations remain independent and the spokesman of their specific topic of interest<sup>[80, 112, 128]</sup>.

The collaboration between LGBTI organisations and NNID causes some more tension between patient organisations and NNID<sup>[24]</sup>. Research by van Lisdonk demonstrated that some intersex people do not identify with the LGBT community, because they view themselves as a separate group<sup>[134]</sup>. Some people are afraid that being associated with LGBT might lead to more questions and confusion about their sexual orientation or gender identity, while this has nothing to do with intersex. The research showed that intersex people did not feel connected with transgender people, because they had no trouble with their gender identity and their assigned sex<sup>[134]</sup>. While NNID acknowledges this, they also find it crucial to seek partnerships on aspects where grievances of LGBT individuals and intersex individuals align<sup>[80]</sup>.

#### 4.4. Conclusion

In this chapter, the aim was to answer the sub-question: *When did the intersex movement emerge in the Netherlands and how did it develop?* The intersex movement in the Netherlands consists of five patient organisations and one patient support group, whose main aim is to provide a support network and to improve the health care of their members. NNID is the first interest group/SMO for intersex people that has a human rights perspective and aims to influence the policy-making regarding intersex. The movement consists of a

40 Translated from Dutch: Ministerie van Volksgezondheid, Welzijn en Sport.

network of organisations and groups, that sometimes work together in coalitions or alliances. Table 4.2 provides an overview of the organisations that were mentioned in this chapter and when they were founded, and it demonstrates that the number of organisations within the intersex movement has increased during the last thirty years. In the next chapter, the results of the discourse analysis will be discussed, which will demonstrate the development of the frames in the public discourse.

| Organisations                          | Founded in (-closed in)        |
|--|--------------------------------|
| COC Nederland                          | 1946                           |
| VSOP                                   | 1979                           |
| Bijni Vereniging-NVACP                 | 1987 (CAH included since 1999) |
| Nederlandse Klinefelter Vereniging     | 1990                           |
| Intersex Society of North America      | 1993-2008                      |
| Stichting MRK-Vrouwen                  | 1999                           |
| Turner Contact Nederland               | 1999                           |
| Trefpunt Hypospadie                    | 2000-2020                      |
| DSDNederland (previously AISNederland) | 2001                           |
| Contactgroep Triple-X Syndroom         | 2004                           |
| Transgender Netwerk Nederland          | 2008                           |
| NNID                                   | 2013                           |

*Table 5.2: an overview of movement organisations.*

## 5. Dutch media discourses: medical or human rights frame?

In this chapter, the second sub-question will be answered: *What discourses do Dutch newspapers construct surrounding intersex?* It will first be demonstrated what the results are regarding the visibility of intersex in Dutch newspapers. Second, the presence of the medical frame and the human rights frame will be discussed, as well as who is responsible for producing those frames.

### 5.1. Visibility

The first aspect that has been researched is the visibility of intersex in Dutch newspapers between 1991 and 2020. In figure 5.1, the number of articles per year is displayed. The figure shows that the number of articles per year fluctuated between 0 and 20 articles between 1991 and 2014. Some years saw a sudden increase of articles, like 1997. This can be explained by the fact that there were two developments regarding Turner syndrome that resulted in six articles. First, research that included women with Turner syndrome demonstrated that girls inherited their language and social skills from their dad's side. Second, the minister for public health no longer compensated a growth hormone for girls with Turner syndrome.

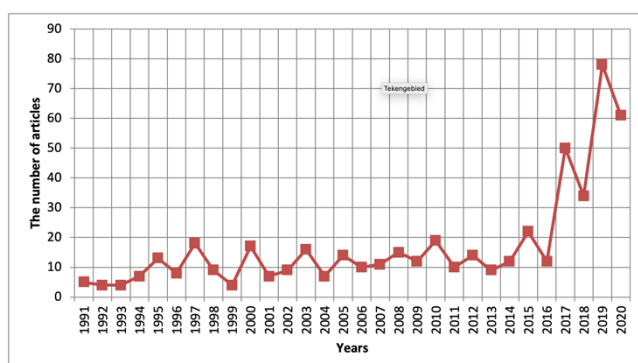


Figure 5.1: The number of articles per year

The increase in the year 2000 can be accounted for by two things: first, it was decided that the blood spot test for babies will also screen for CAH and second, there seemed to be more attention for hypospadias because people wanted to investigate why hypospadias occurred. In 2003, two things can explain the number of articles. First, Jeffrey Eugenides wrote the book *Middlesex*, which is about an intersex person. This book received a lot of attention, and eventually also won the Pulitzer Prize. Secondly, the program *Vinger aan de Pols* aired with an episode about intersex people with AIS. This was the first time intersex was discussed on television, as discussed in Chapter 4. This led to one long-read article, and one mention in the television guide of one of the newspapers. In addition, an article discussing surgeries on intersex children was published, to which urologist Tom de Jong responded with an opinion piece.

From 2005 onwards, the number of articles remains at ten or above, but in 2013 only nine articles were published. In 2017, there is a large increase in the number of articles. There are three reasons for this. First, Raven van Dorst announced that they are intersex in their television program. This resulted in eight articles. Second, a discussion about gender-neutral language arose, which led to

multiple articles about this topic. Lastly, the addition of 'I' to LHBT led to more visibility of intersex in Dutch newspapers, because the abbreviation LGBTI was regularly used by newspapers. This meant that intersex was mentioned even when the article did not necessarily discuss intersex matters.

In 2019, the large number of articles can partially be ascribed to the fact that *AD/Algemeen Dagblad* posted their regional articles on their main website, which is why they ended up in the data set. Although most articles discuss regional matters, these articles are nationally available through the website of *AD/Algemeen Dagblad*, which means that they influence the public discourse. Most of these regional articles discuss policy plans of cities or municipalities regarding LGBTI matters. Intersex remains visible due to the LGBTI abbreviation.

Although a steady upward trend cannot be shown, it is evident that since 2017 the number of articles has largely increased and this can mainly be ascribed to the fact that the 'I' has been added to the LGBTI abbreviation which has led to more visibility of intersex. 2017 is also the year that NNID formed an alliance with *COC Nederland* and TNN. With both *COC Nederland* and TNN also including intersex in their interest representation, intersex is no longer only visible when articles are about intersex, but also when *COC Nederland* or TNN talk about LGBTI issues in the media.

### 5.2. Discourses in Dutch newspapers

In this section, the results of the CDA regarding the concepts of standing and framing will be shown. This part is divided into two sections: first, this part elaborated on the development of the medical frame, and then the development of the human rights frame will be discussed. For a more detailed description of both frames, see table 3.1.

#### 5.2.1. Medical frame

From 1991 to 2003, the medical frame is the dominant frame that is used when intersex is discussed. Medical professionals have standing with the media in this period because they are the only ones that are being directly and indirectly quoted. Most of these articles are about Turner syndrome, Klinefelter syndrome, hypospadias or CAH. The articles have a medical frame because they talk about these intersex variations in terms of 'illnesses' or 'deviations'. Thereby indicating that Turner syndrome, Klinefelter syndrome, hypospadias and CAH are medical conditions, that need treatment.

Patient organisations do not have standing, although the *Nederlandse Klinefelter Vereniging* is mentioned once in 1997[3]. In addition, a girl with Turner syndrome is directly quoted in an article in the same year. However, this article has a medical frame because it emphasises that girls with Turner syndrome have a 'deviant' length compared to other girls. It is also expressed how 150 cm is the acceptable length in society, while most girls with Turner syndrome are shorter. From a human rights perspective, it would be argued that society needs to change, rather than those girls, but



this article argues that girls “don’t count”<sup>41, 42</sup> if they are shorter than 150 cm which presents a medical frame[87].

The first article that has intersex as its main topic appears in 1998. This article is written from a medical frame, as the statement at the beginning of the article illustrates: “Their motto is: after determining the sex, operate as quickly as possible to end the debilitating uncertainty of the parents”<sup>43</sup>. ‘Their’ refers to the doctors who are being quoted in this article[27]. This quote is exemplary of the medical frame, as it argues that the sex of intersex children should be determined as quickly as possible after which surgery is necessary to soothe the parents. Moreover, the article refers to the intersex movement in the US as a ‘militant group’. The doctors in this article do not agree with the standpoints from a human rights perspective of the intersex movement.

Another clear indication of the medical frame is evident in articles about CAH. Girls with ‘masculine’ external genitalia are depicted as a problem that needs fixing. An article with the title “Heel prick keeps girls more feminine”<sup>44</sup> discusses how girls with CAH often need immediate surgery to fix the external genitalia. CAH can be deadly because in most extreme cases, if not diagnosed quickly, it can cause a salt-wasting crisis which can be fatal[65]. This article emphasises the external genitalia are a problem, rather than the hormone deficits that cause huge health risks[5]. This is typical of the medical frame, wherein the genitals of intersex children are seen as a medical problem.

In 2003, the medical frame is presented in an article about surgeries on intersex children[101]. Medical professionals, who are in favour of ‘correcting’ intersex bodies and reproduce the male-female binary, are quoted: “A child according to Vulsma<sup>45</sup> is always a boy or a girl. ‘That is my prepossession. And the majority of my colleagues thinks this too.’”<sup>46</sup>. Moreover, the parents of an intersex child are interviewed, and they explain that they have a “good feeling”<sup>47</sup> about the surgery and they argue: “If a child at birth has a cleft-lip, the parents also have it corrected”<sup>48</sup>. The frame is challenged by cultural scientist and researcher Margriet van Heesch<sup>49</sup>. Van Heesch articulates a human rights frame by arguing: “It is not a medical problem, it is a cultural problem.”<sup>50</sup>. The intersex person who has been interviewed for the article is deeply unhappy with the medical treatment she received as a child and adds: “Keep your hands of intersex children unless it is medically absolutely necessary.”<sup>51</sup>. Nevertheless, the article has an overarching medical frame.

Two weeks later the newspaper publishes a response to this article by urologists Tom de Jong who does not agree with Van Heesch’s statements. He argues that: “The sex identity of intersex children is

certainly a medical problem, that will not become any less of a problem if you postpone treatment”<sup>52</sup>. He defends the current medical practices by arguing that those who are unhappy have been treated based on ‘old’ procedures that are no longer in use. He continues by saying that Van Heesch does not know what she is talking about and that the article was based on one-sided informed journalism. This commentary demonstrates a medical frame because De Jong is in favour of surgeries on intersex children and says it is not only medically necessary but also socially necessary[29].

The medical frame is not only articulated by medical professionals, but sometimes also intersex people themselves reproduce the frame by using certain words or statements that make it seem like intersex is a medical problem. For example, in an article about MRKH-syndrome, a woman refers to it with the term ‘deviation’, which indicates a medical frame: “She did not understand how this deviation could have originated”<sup>53</sup>. Moreover, the women say: “I keep feeling that I am not a real woman.”<sup>54</sup> and “I felt incomplete, not a woman.”<sup>55</sup>. The idea that a woman’s body is incomplete without certain reproductive organs is a perspective that underlies the medical frame because it finds that female bodies should have certain characteristics to be able to qualify as a ‘normal’ female body.

In 2005, brain scientists Dick Swaab argues that doctors should wait to operate until intersex children are at least four years old, which is when, according to him, the gender identity of the child can be determined more accurately. Swaab argues that people can become deeply unhappy if the wrong choice of sex and surgical intervention is being made: “A wrong choice can destroy a whole life. The stories of people by whom that happened are very sad.”<sup>56</sup>. Although Swaab says that operating on intersex children can destroy a person’s life, he does not argue against operating on children. This means that although Swaab is against the current medical practices, he does not uphold a human rights frame because that frame is against surgeries on children until they are old enough to decide what they want. Furthermore, this article has a medical frame because the doctors, who are directly quoted, are critical of Swaab’s statement and defend their surgical interventions. For example, Tom de Jong criticises the research of Van Heesch again and argues that decisions are made in a lot of deliberation with other medical professionals, psychologists and the children’s parents[66].

From 2006 until 2011, the medical frame is dominant. This is demonstrated by for example how the term ‘suffering’ is often used whenever articles discuss Turner syndrome. It implies that Turner syndrome is an illness that you suffer from. Furthermore, discussion

41 Poll, M. (1997, November 8). Turner: de strijd om centimeters. NRC Handelsblad.

42 All quotes have been translated from Dutch to English. Original quotes are in possession of NNID and can be requested at any time.

43 Danhof, E. (1998, March 6). Interseks: schipperen tussen m/v; ‘Het is geen jongetje, maar ook geen meisje’. Algemeen Dagblad.

44 Baart, S. (2000, May 13). Hiepruk houdt de meisjes vrouwelijker. De Volkskrant.

45 Tom Vulsma is a pediatrician-endocrinologist in the Academic Medical Center (AMC) in Amsterdam.

46 Snoeijen, M. (2003, May 10). De derde sekse; De onzekere wereld van kinderen en mensen zonder een duidelijk geslacht. NRC Handelsblad.

47 Ibid

48 Ibid

49 Margriet van Heesch is a cultural scientists at the University of Amsterdam. She did her dissertation about the experiences of intersex people.

50 Snoeijen, M. (2003, May 10). De derde sekse; De onzekere wereld van kinderen en mensen zonder een duidelijk geslacht. NRC Handelsblad.

51 Ibid

52 de Jong, T. (2003, May 24). Chirurgen niet snijgraag. NRC Handelsblad.

53 Trouw. (2005, September 3). Geboren met een buik zonder baarmoeder; Kinderloosheid. Trouw.

54 Ibid

55 Ibid

56 Koelwijn, J. (2005, July 23). Tussen jongen en meisje; BABY MET ONDUIDELIJK GESLACHT MOET SNEL WORDEN GEOPEREERD. OF TOCH NIET ? NRC Handelsblad.

arises about intersex people in sports due to the South-African athlete Caster Semenya. The athlete had to undergo a sex test to determine her 'true sex' because otherwise she is not allowed to compete in the women's competition. Articles focus on what characteristics determine whether you are a man or a woman and that there is a 'normal' level of testosterone that the female body should make<sup>[36, 62]</sup>. The idea that human bodies can fit a binary norm based on certain bodily characteristics is typical for the medical frame.

Another interesting way in which the medical frame is amplified is when in an article about intersex, doctors are quoted to 'clarify' what Van Heesch is explaining about the secrecy protocol: "'Until the '70s it was common for doctors to inform patients little by little,'" clarifies the paediatrician-endocrinologist Sten Drop from Rotterdam."<sup>57</sup>. Although Van Heesch is directly and indirectly quoted in this article, the doctors seem to have more standing with the journalist because they need to explain what Van Heesch said. It shows that intersex is still seen as a medical issue, rather than a societal issue because doctors are seen as the experts about intersex issues rather than Van Heesch.

2012 is the first year that the medical frame is less visible than the human rights frame. However, the medical frame is still expressed by some people. For example, parents of intersex people tend to speak in binary terms: "born as a 'perfect boy', on whose body nothing deviant was visible"<sup>58</sup>. Speaking in terms of a 'perfect boy' and 'deviant' assumes that intersex bodies are not perfect and are deviant from what is considered to be 'normal', which is characteristic of the medical frame. Furthermore, in another article a doctor is being quoted: "In a situation like that more research is usually necessary to determine the sex. It also happens that we postpone the decision, or that later, when the child grows up, another choice is made."<sup>59</sup>. This quote presents a medical frame because the doctor implies that a choice is made for the child rather than that the child can decide for themselves.

In 2013, the chair of *DSDNederland* is directly quoted in an article about intersex and sports: "The surgery on the women's genitalia. That can be seen as a human rights violation, according to Juliette Kuling, chair of DSD Nederland [...] We have to deal here with doctors who think that besides castration, they also must cut in the clitoris. Like these four women can otherwise not be a woman."<sup>60</sup>. This quote indicates a human rights frame because it speaks out against surgery on intersex women and argues that intersex women can be women without undergoing surgery. However, after this quote a doctor says: "Reconstructing the genitalia, well, that's obviously not necessary for sports."<sup>61</sup>, which implies that in other cases reconstructing genitalia is necessary. This article has a medical frame because, besides the contribution of *DSDNederland*, only medical professionals are quoted who express a medical frame<sup>[37]</sup>.

In 2015, the medical frame is expressed again in an opinion piece by Tom de Jong and Concetta Salvatore, both doctors, in response to articles about the dissertation of Van Heesch<sup>[30]</sup>. They say about Van Heesch: "It is regrettable that she did not inform herself by the surgeons of children with Disorders of Sex Development (DSD), the child-urolologists and child-gynaecologists."<sup>62</sup>. About surgeries on intersex children they write: "Let it be clear that every year hundreds of children receive surgery on their genitals based on good reasons with excellent results and without consequences for their psychological or sexual functioning later on in life."<sup>63</sup>. In the remaining of the article, they defend the medical practices that treat intersex and argue that the decision to operate is carefully considered and made in multidisciplinary-DSD-teams. This piece is written from a medical frame because they argue that medical professionals should be asked about intersex issues and that certain surgeries or corrections are necessary for intersex children.

From 2016 onwards, the medical frame is less visible than the human rights frame. Although, one interesting article that expresses the medical frame is an article about a pill for CAH. This pill had the goal to reduce the 'masculinisation' of the 'female genitalia' of girls with CAH. The journalist finds it puzzling that this pill is still being used, because of the lack of research into the side effects of the pill. The pill is still prescribed in the Netherlands, which indicates that fixing intersex bodies is more important than the undocumented side-effects of the pill<sup>[107]</sup>. The journalist is aware of the binary standards that are maintained with this pill: "This is a story about the taboo on children who do not fit in the boxes of 'boy' or 'girl'"<sup>64</sup>. While the journalist acknowledges that there is a taboo on intersex children, thereby articulating a human rights frame, she does not discuss this in the article. Therefore, the article has an overarching medical frame because the seemingly 'normal' medical practice of changing intersex bodies to fit the norm is not further challenged, which reproduces the medical frame.

In 2018, it becomes evident that some doctors stop presenting a strong medical frame. For example, one doctor acknowledges that sex and gender are not binary, but explains that if she tells parents that they no longer operate on intersex children:

*[...] then we have to ensure that society accepts this as well. There is more than male and female, I see that in the hospital every day. And if we continue to correct it, then society keeps thinking that there is only male and female. Doctors and society should talk about this. In principle, I agree with human rights activists, but we want to determine the treatment per individual case.*<sup>65</sup>

This article also interviews some parents of intersex children or intersex children themselves who say they are happy with the medical interventions and a doctor who is in favour of operating on intersex children, whom all present a medical frame.

57 de Visser, E. (2010, May 22). Kiezen om te leven als man, als vrouw of allebei tegelijk. Veel DSD-patiënten hebben het wel gehad met dokters. De Volkskrant.

58 Toonen, A. (2012, May 11). Een puntgaaf jongetje, en meisje in één; Thijs werd Maya en mag zich zonder geslachtsoperatie als vrouw laten registreren. NRC Handelsblad.

59 NRC Handelsblad. (2012, May 11). Jongen of meisje? Bij sommige baby's blijft die vraag. NRC Handelsblad.

60 de Visser, E. (2013, May 25). De strijd om de sekse. De Volkskrant.

61 Ibid

62 de Jong, T., & Salvatore, C. (2015, June 6). De rubriek U is een podium voor lezers. De Volkskrant.

63 Ibid

64 ten Broeke, A. (2016, June 4). Normale meisjes maken. De Volkskrant.

65 Peters, L. (2018, April 7). "Het is een meisje!", zegt de vroedvrouw na de bevalling tegen moeder Tjitske. Maar de arts die even later aan het bed staat, feliciteert haar met een zoon. De Volkskrant.

### 5.2.2. Human rights frame

2003 is the first year an article is published with a human rights frame that is specifically about intersex. This article consists of an interview with Inge Intven and Miriam van der Have and it discusses the experiences of two women with AIS[140]. Both women argue that they are against surgeries on intersex children. The journalist reproduces this perspective: "Because unfortunately, it happens very often that doctors, whenever it is not clear whether it is a girl with a large clitoris or a boy with a small penis, that they just put a knife in it."<sup>66</sup>. It is unclear whether this is an indirect quote, so it seems like the journalists took over the human rights frame by using the word 'unfortunately', implying that it is not a good thing that doctors operate on intersex children. Moreover, the patient organisation *AISNederland* is mentioned, as well as the goals of the organisation are discussed. This article can be seen as an example of when intersex people are interviewed, and not medical professionals, which causes the human rights frame to become dominant.

In 2003, a few direct quotes from Van Heesch in an article about surgeries on intersex children present a human rights frame. Van Heesch claims that it is not necessary to operate on children with hypospadias, since the benefits do not outweigh the problems these people experience:

*Research shows that these boys are usually not happy with the surgery. [...] But some doctors simply think that parents want a child with 'normal' genitalia. [...] The surgeon decides how a penis or clitoris should look like. For a doctor, a girl with a vagina that looks like a penis is a cultural emergency, not a medical emergency.*<sup>67</sup>

Furthermore, Van Heesch states that no research justifies the surgeries on intersex children without their consent and that no research demonstrates that intersex people are content with their surgery when they are older. In addition, the health law ethicist that is directly quoted in this article argues that it is better to not surgically interfere: "It is better to recognise sexual ambiguity than to push it away."<sup>68</sup>. However, this article still has a medical frame and it is criticised with an opinion piece by Tom de Jong two weeks later (see the previous section).

*Stichting-MRK-Vrouwen* is mentioned in an article in 2005. This article interviews a woman with MRKH-syndrome, who expresses a human rights frame: "The MRKH-syndrome is just a part of me and they should take me as I am."<sup>69</sup>. At the same time, a medical frame is present, for example, a medical professional is directly quoted[33]. Moreover, the journalist uses words like 'condition' and 'normal' to indicate that women with MRKH-syndrome "look completely normal"<sup>70</sup> from the outside, which implies that 'normal' women look a certain way.

In 2005, an opinion piece by Miriam van der Have, as chair of *AISNederland*, is published[122]. The article is a response to the article in which surgeries on intersex children were discussed after Swaab

criticised early surgeries on these children. Van der Have argues that patient organisations are against most medical interventions, especially those that are merely done for cosmetic reasons. *AISNederland* argues that as long as it cannot be determined for a hundred per cent that a child is either a boy or a girl, surgery should be postponed. Children should be able to decide whether they want surgery[122]. The article has a human rights frame because Van der Have states to be against medically unnecessary non-consensual surgeries and the right of children to decide themselves.

After 2005, it takes until 2012 for the human rights frame to become visible in the public discourse again. In 2012, Maya Posch becomes the first Dutch person to legally change her registered sex without having to undergo genital surgery. Posch was born intersex, registered as a boy at birth and now identifies as female[108]. In an interview, Posch expresses a human rights frame. She says she is against the term DSD, because "[...] it is not a disorder, it is a natural phenomenon"<sup>71</sup>. She is also against operations on intersex children and argues that children themselves should be able to decide whether they want to be operated on or not: "Leave those children to grow up first and then let them later decide what they want."<sup>72</sup>

The discussion about intersex and sports resumes in 2012. Sports historian Max Dohle has a human rights perspective on the issue of whether intersex athletes have to undergo medical treatment, such as lowering their testosterone levels. He writes that testosterone is not the most important factor that determines an athletes' success: "It has not been scientifically proven that winners have a higher testosterone level than losers. Testosterone is in fact not a good prediction for sports success."<sup>73</sup>. He argues that someone's body length or long limbs are important contributing factors to whether someone can be a successful athlete. He ends his article by saying that sex tests should be abolished completely[40]. This article is written in a human rights frame because Dohle argues that bodies come in all kinds of natural variations and that no one should have to alter their body to be allowed to participate in sports competitions.

In 2014, the rapport 'Living with intersex/DSD' is published. The article explains intersex in rather medical terms, such as 'condition' and 'usual': "There are a lot of forms of this condition [...]. Some women have the usual XX-chromosomes and ovaries but are born without (a complete) vagina or uterus."<sup>74</sup>. However, the researcher, who is quoted in this article, emphasises the importance of making intersex people more visible in society[90]. This shows a human rights frame because it discusses the social experiences of intersex people.

Another article in 2014 that demonstrates a human rights frame, is an interview with Juliette Kuling who appears with her personal story in the newspaper[91]. Although Kuling uses a human rights frame, the journalist reproduces the medical frame by writing that

66 Wierstra, R. (2003, December 3). MAN van binnen. De Telegraaf.

67 Snoeijen, M. (2003, May 10). De derde sekse; De onzekere wereld van kinderen en mensen zonder een duidelijk geslacht. NRC Handelsblad.

68 Ibid

69 De Telegraaf. (2005, August 3). "Geen kinderen, dat is het ergste!" De Telegraaf.

70 Ibid

71 Toonen, A. (2012, May 11). Een puntgaaf jongetje, en meisje in één; Thijs werd Maya en mag zich zonder geslachtsoperatie als vrouw laten registreren. NRC Handelsblad.

72 Ibid

73 Dohle, M. (2012, July 30). Topsport is zuiverder zonder geslachtstest. De Volkskrant.

74 Pronk, I. (2014a, June 18). Als de artsen het al niet weten. Trouw.

with Kuling it went “different”<sup>75</sup>, which implies that there is a ‘normal’ way how things should go. Kuling does not see it like that: “there is more between XX and XY. And chromosomes are not determinative for your gender identity. It has to come out of the shadows, out of anonymity”<sup>76</sup>. The focus of this article is on the fact that Kuling had to keep her being intersex a secret and how she wants to ensure that it becomes more common knowledge among the general public. This demonstrates a human rights perspective on intersex.

2014 is also the first year wherein NNID has two articles published in the newspaper, written by Miriam van der Have as chair of NNID. The first one is an opinion piece about Canal Pride in Amsterdam, and why the ‘I’ of intersex should be added to the abbreviation ‘LGBT’<sup>[123]</sup>. She discusses why intersex has been invisible for a long time, and how some people still view intersex as an ‘illness’. Van der Have mentions the human rights reports of the United Nations and the European Union that call ‘normalising’ surgeries on intersex children a human rights violation: “In short: internationally intersex is not seen as a medical problem, but as a human rights problem”<sup>77</sup>. Van der Have argues for including ‘I’ into the abbreviation LGBT because it strengthens the process of equality and visibility for the intersex community<sup>[123]</sup>. Moreover, the human rights frame is present in the following quote: “Personally I find it more important to explain that Gay Pride is there for people who need it and not for those people, who for whatever reason, are against it”, because the human rights frame argues that intersex people can decide for themselves whether they want to be a part of the LGBTI community.

The second opinion piece is a response to an article about women in sports<sup>[124]</sup>. Van der Have argues that medical treatment for intersex women in sports is absurd: “These women are not allowed to participate in sports without medical intervention. The requirement to lower their androgen levels is just as nonsensical as demanding from Usain Bolt to remove a part of his legs.”<sup>78</sup>. This quote demonstrates a human rights frame, as she argues that people should not have to undergo medical treatment to fit their bodies to a certain norm.

In 2015, three articles are written about the dissertation of Van Heesch. Each article presents a human rights frame and neither of the articles includes quotes from medical professionals. The first article includes an interview with Van der Have about her intersex experiences<sup>[85]</sup>. It is mentioned that she is the chair of NNID and a human rights activist. She describes how society has an issue with intersex: “Society finds it scary and wants you to be either a man or a woman. The outside world teaches you that you cannot talk about it.”<sup>79</sup>. Van der Heesch argues that there are still doctors who perform surgeries on intersex children, and that this should end and

that it is important to wait for the child to grow up and make their own decision<sup>[85]</sup>.

The second article uses a medical frame to explain intersex by referring to words such as ‘normal’ to differentiate between what is considered ‘normal’ and what is intersex: “But there are also children with a normal amount of chromosomes who still develop an ambiguous sex genital.”<sup>80</sup>. Van Heesch is directly quoted and states that no one fits into the strict binary norms of society<sup>[137]</sup>, and the journalist acknowledges that: “the biological division between men and women is not as sharp as we have always thought; the difference is rather gradual”<sup>81</sup>. This quote demonstrates a human rights frame because it says that bodies come in a wide variety of forms.

The third article has the clearest human rights perspective. The title alone shows this: “Early sex operations do not help”<sup>82</sup>. This article has the form of an interview, which allows Van Heesch to give some longer answers<sup>[136]</sup>. About surgeries on intersex children she says:

*I can't tell you to what extent early surgeries still occur, but there are still surgeries to reduce clitorises because they are too big, let's say: to normalise them. Especially boys with a short urethra often receive surgery. This is a mild form of intersex (hypospadias). But the norm is that boys must be able to pee while standing up. Otherwise, the urethra is made longer, which often causes complications.*<sup>83</sup>

She also argues that intersex is not an illness: “Medicalising is maybe not the best option, because intersex is not an illness. You won't die from it and it cannot be cured.”<sup>84</sup>. This quote is exemplary of the human rights frame because it does not view intersex as an illness. This article provokes the response by Tom de Jong and Concetta Salvatore, which has been discussed in the previous section.

The human rights frame is present again in 2016. Three parliamentary members publish an opinion article about extending the General law on equal treatment<sup>85</sup> to include sex characteristics, gender identity, gender expression and sexual orientation. They argue it is necessary to explicitly forbid discrimination towards transgender and intersex people<sup>[9]</sup>. This article has a human rights frame, because they say: “And too often unnecessary surgeries follow, that are only focused on making sure that bodies comply to the strict norm of men or female.”<sup>86</sup>. They want to ensure that those who do not fit in the strict male-female binary norm are also protected by the law against discrimination.

Moreover, an article about the disappearance of sex registration in official governmental documents cites a quote of NNID about this development<sup>[94]</sup>: “This is very important for a particular group of people. For them, it can be very unpleasant to be on the train and have a conductor look at your card and say that your sex

75 Pronk, I. (2014b, June 18). Het is met Juliette niet “fout” gegaan, maar “anders.” Trouw.

76 Ibid

77 van der Have, M. (2014a, August 1). Ook wij varen mee in Canal Parade. Het Parool.

78 van der Have, M. (2014b, October 14). Brieven; Onterecht buitengesloten. NRC Handelsblad.

79 Pen, H. (2015, May 29). Er zijn meer smaken dan man of vrouw. Het Parool.

80 Voormolen, S. (2015, July 25). Ergens tussen man en vrouw; Seks en de mens. NRC Handelsblad.

81 Ibid

82 Vermeulen, M. (2015, June 1). ‘Vroege sekseoperatie levert niets op’. De Volkskrant.

83 Ibid

84 Ibid

85 Translated from Dutch: Algemene wet gelijke behandeling

86 Bergkamp, V., Keklik, Y., & van Tongeren, L. (2016, August 8). Er is zoveel meer dan man en vrouw. NRC Handelsblad.

registration is wrong.”<sup>87</sup> This article has a human rights frame because it emphasises the benefits of reduced sex registration, which impacts the experiences of intersex people.

The human rights frame has already become more visible since 2012, but the difference between the visibility of the medical frame and the human rights frame grows rapidly in 2017. This can be partially accounted for by the fact that medical professionals are rarely quoted. Furthermore, the already famous Dutch television presenter and musician Raven van Dorst announces that they are intersex. In an interview, Van Dorst mostly expresses a human rights frame by, for example, arguing that they do not fit the male-female binary and “that there is more than men and women; it is not that binary”<sup>88</sup>. In contrast, the journalist expresses a medical frame by asking questions that reproduce the male-female binary[132]: “Did you ever think: I wish I was a boy?”<sup>89</sup> and “Was it a logical choice that you became a girl?”<sup>90</sup>. Besides, “after some insistence”<sup>91</sup> of the journalist, Van Dorst gives medical information about themselves. This demonstrates a medical frame because the journalist views medical information as something relevant to discuss when it is about intersex.

One article in 2017 is interesting since it is the first time that a medical professional with a human rights perspective is quoted. The article is about Human Rights Watch, which advocates for forbidding surgeries on intersex children in the US[21]. “The medical opinions remain divided. Doctor Safer thinks that children should decide themselves when they are older: ‘The doctor’s motto ‘don’t do harm’ prevails.”<sup>92</sup>. This quote shows a human rights frame, arguing that children’s bodily integrity is an important right and that doctors have a responsibility to protect that.

In an article about surgeries on intersex children in 2018, it is interesting to see that the journalist has chosen to put certain stigmatising words between brackets, such as: ‘correcting’ ‘deviation’ ‘normal boys and girls’[86]. This shows that the writer is aware that these words reproduce a certain norm. NNID is also directly and indirectly quoted in this article, presenting a human rights frame by stating that they are against non-consensual and medically unnecessary surgeries by intersex people: “It is easier to reverse a social and legal sex than a surgery.”<sup>93</sup>.

2019 is also the first year when the alliance between NNID, TNN and COC Nederland is visible in the newspaper. As an alliance, they respond to, for example, the political developments regarding the gender-neutral passport[74]. In 2020, the alliance is cited in three articles about sex registration on the identity card[1, 35, 115]. Each of these articles has a human rights frame because only organisations that are in favour of the limitation of sex registration by the government are quoted.

In 2020, there are a few important events for the intersex movement. Firstly, the city of Utrecht signs the intersex declaration.<sup>94</sup> The declaration is an initiative from NNID and the municipality of Utrecht. Two articles are written about this, one cites NNID[135] and the other does not even mention the organisation[34], even though the declaration is an initiative of NNID, which shows NNID has not generated standing with this particular newspaper.

Secondly, a documentary about intersex, *jongensmeisjesmix*, is released, which leads to the publication of two articles. One has a human rights frame and states that current norms regarding sex and gender should be changed. NNID is only mentioned as an information source in this article[61]. The other article also interviewed medical professionals, which shows intersex is perceived as a medical issue. NNID is not quoted, but the standpoints of the organisation are explained. Intersex is explained as a ‘natural phenomenon’[64], which fits with a human rights frame. This article has both elements of the human rights frame and the medical frame. Again, the fact that a medical professional was asked to comment on intersex issues, demonstrates that intersex is still seen as something medical rather than strictly social.

The year 2020 ended with an article about intersex and non-binary, and how in 2020 both concepts became more known to the general public[96]. In this article, NNID is directly quoted: “Where intersex was a specific topic at first, mainstream attention was given to it in 2020”<sup>95</sup>. The remaining article is mainly about non-binary people, but the article, in general, argues that intersex became an important topic in 2020. It has a human rights frame, because it does not medically refer to intersex but discusses the societal developments regarding intersex.

### 5.3. Conclusion

Figure 5.2 presents an overview of the number of times a medical frame or a human rights frame was visible in articles that had intersex as their main topic. The articles that did not have intersex as their main topic were excluded, to prevent a skewed picture of the changing discourse about intersex.<sup>96</sup> Figure 5.2 shows that from 2017 onwards the human rights frame is dominant in the public discourse, while before 2014 the medical discourse was dominant.

This also answers the sub-question: *What discourses do Dutch newspapers construct surrounding intersex?* Before 2014, Dutch newspapers generally used a medical frame when discussing intersex and intersex issues, which made the discourse about intersex depict it as a medical issue. Since 2017, Dutch newspapers have mostly used a human rights frame when discussing intersex and intersex issues, which constructs a discourse that perceives intersex as a social issue.

87 Rosman, C. (2016, December 24). M/v doet op post en pasjes niet meer mee. Het Parool.

88 van Dongen, M. (2017, February 11). “Als het maar geen jankverhaal wordt.” De Volkskrant.

89 Ibid

90 Ibid

91 Ibid

92 Claus, S. (2017, July 27). Als het hokje man/vrouw niet opgaat. Trouw.

93 Peters, L. (2018, April 7). “Het is een meisje!”, zegt de vroedvrouw na de bevalling tegen moeder Tjitske. Maar de arts die even later aan het bed staat, feliciteert haar met een zoon. De Volkskrant.

94 Translated from Dutch: De Nederlandse Intersekseverklaring.

95 Sedee, M. (2020, December 23). Meer ruimte tussen man en vrouw; Lhbt; In 2020 braken “X” en “die” door. NRC.NEXT.

96 For example, articles that were about LGBTI issues presented a human rights frame, but often were not specifically about intersex and therefore tell us more about the public discourse about LGBTI in general than about intersex issues specifically.

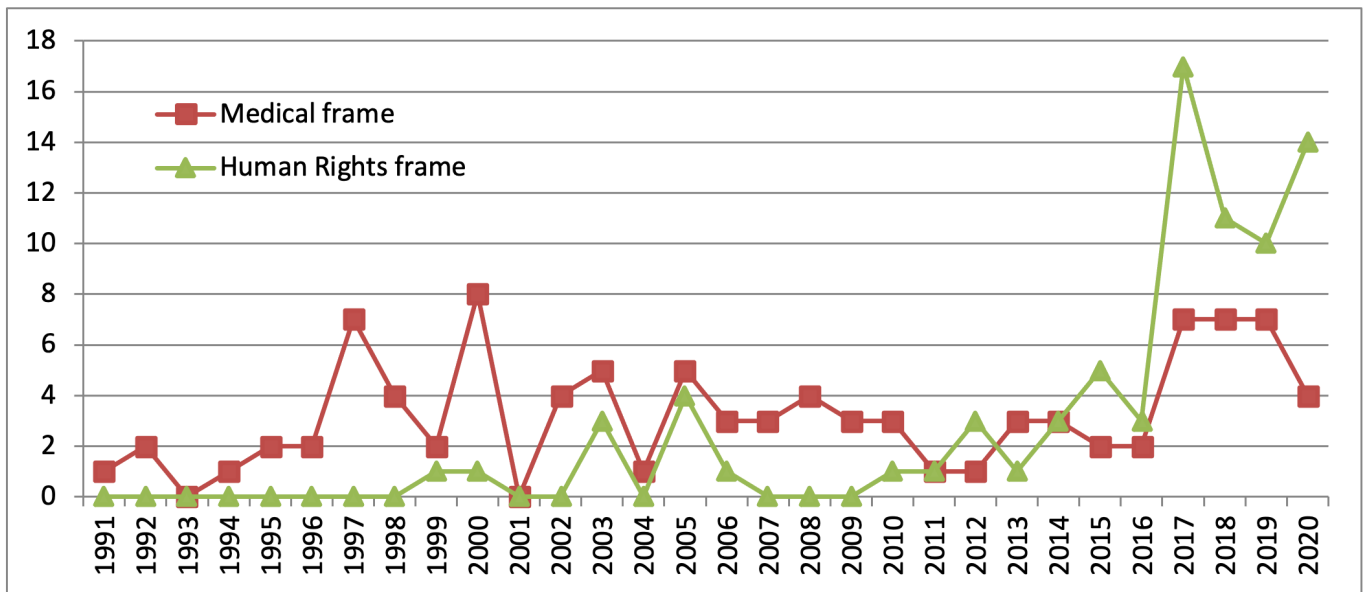


Figure 5.2: the presence of the medical frame and the human rights frame in articles about intersex

## 6. Conclusion

This research aimed to find out to what extent the intersex movement in the Netherlands influenced the discourses about intersex in the Dutch media. To find an answer, desk research and a CDA were conducted to investigate the two sub-questions: *When did the intersex movement emerge in the Netherlands and how did it develop?* and *What discourses do Dutch newspapers construct surrounding intersex?* In this final chapter, the answers to the research questions will be discussed and the findings will be compared to the hypotheses that were formulated in Chapter 2. Thereafter, the implications and limitations of this research will be explained, as well as some recommendations for further research.

### 6.1. Research question

#### 6.1.1. First sub-question

The aim of Chapter 4 was to provide an overview of the emergence and development of the intersex movement in the Netherlands. Desk research indicated that the Netherlands has five patient organisations: *Turner Contact Nederland*, *Nederlandse Klinefelter Vereniging*, *DSDNederland*, *Bijniervereniging-NVACP* and *Stichting MRK-Vrouwen*, and one patient support group: *Contactgroup Triple-X Syndroom*. The Netherlands has one interest group/SMO, which is NNID. These organisations form the intersex movement in the Netherlands. Whereas the patient organisations perceive intersex as a medical issue, NNID views intersex as a social issue. Although these organisations have some opposing ideas, they do work together on common goals, such as providing information about and destigmatising intersex. NNID has also worked together with two LGBTI organisations since 2017. These organisations work together to change the norms regarding heteronormativity, and the sex- and gender-binary.

#### 6.1.2. First hypothesis

Chapter 5 presented the results of the CDA in which three elements were investigated: visibility, standing and framing. The results regarding visibility demonstrated that intersex became more visible between 1991 and 2020, with an increase from 2017 onwards. Based on these findings, the first hypothesis, *the longer the movement exists and the more developed it becomes, the more media attention it attracts*, can be confirmed. The increased visibility of intersex in the media can, for a large part, be ascribed to the addition of the 'I' to the LGBTI abbreviation, and the alliance between the three LGBTI organisations. Both caused intersex to be mentioned in articles that were not explicitly about intersex.

As explained in Chapter 2, being part of a social movement network can benefit a single SMO because it provides the organisations with more resources such as having contact with more different journalists or being affiliated with organisations that are already more validated by the media. The alliance between NNID, *COC Nederland* and TNN influenced the development of intersex being mentioned in articles that were not necessarily about intersex issues, but about LGBTI issues in general. The collaboration between these organisations brought the costs down to attract media coverage. Rather than each organisation separately having to use resources to generate media attention, now one organisation can do so or they can combine their resources. This

especially benefits a newer SMO like NNID, in comparison to an organisation like *COC Nederland*, that has had a longer period to attain resources and use them to become a validated actor by the media.

#### 6.1.3. Second hypothesis

The results regarding standing and framing in Chapter 5 showed that some patient organisations have had standing with the media such as *AISNederland/DSDNederland*, but no other patient organisation has generated standing with the media. NNID is quoted the most often in comparison to the patient organisations, which shows that NNID has generated some standing with the media. At the same time, there were some articles about intersex, wherein NNID is not mentioned nor quoted. It was especially striking that NNID was not mentioned in an article about the intersex declaration, an initiative by NNID. This demonstrates that NNID has not been able to generate consistent standing with the media. The second hypothesis, *the longer the movement exists and the more developed it becomes, the more standing with the media it can generate*, can be partially confirmed.

The ability of NNID to generate standing with the media has been influenced by their alliance with *COC Nederland* and TNN. These organisations have already gained more standing with the media, especially *COC Nederland* is regularly quoted in articles about LGBTI issues. According to the theoretical framework, organisations that have more organisational resources, such as employees that had the time to establish relationships with journalists, are more likely to generate standing with the media. The alliance with these organisations benefits NNID because they profit from *COC Nederland* and TNN that have already generated standing, which increases the likelihood of NNID also attracting standing with the media.

#### 6.1.4. Third hypothesis

The framing of intersex issues in the media is largely dependent on who is being quoted. The analysis showed that NNID has always articulated a human rights frame when they were quoted in the media, while the appearance of the medical frame was largely dependent upon the presence of medical professionals in the articles. On the one hand, their sole presence in an article indicates that intersex is something medical, otherwise, a journalist would not ask a medical professional for their opinion. On the other hand, medical professionals still perceive intersex as a medical issue, and thus still discuss the medical treatments 'necessary' to fix intersex bodies. From 2017 onwards, medical professionals are less often quoted when intersex is being discussed. This shows that medical professionals are no longer seen as the only expert about intersex issues. Other actors, such as NNID or intersex people, are increasingly recognised as having authority over this topic. This has resulted in the human rights frame becoming more visible in the public discourse. Consequently, the third hypothesis, *whenever a social movement has received standing with the media, the more likely it can influence the framing*, can be confirmed.

At the same time, the increased visibility of the human rights frame cannot be entirely ascribed to the existence of NNID and their alliance with *COC Nederland* and TNN. What becomes evident from



taking a closer look at the topics of the articles between 2017 and 2020 is how issues, like gender-neutral language and the gender-neutral 'X' option in official governmental documents, are more often discussed. These topics are often connected to intersex issues. It seems like the general public discourse regarding sex-, gender- and LGBTI-issues have had a positive influence on the visibility of intersex. It could also be that the increased visibility of intersex issues in the public discourse has had a positive impact on discourses about sex-, gender- and LGBTI-issues. Therefore, further research should look at the relationship between general sex-, gender- and LGBTI-discourses and intersex discourses, and to what extent they influence each other.

### 6.1.5. Second sub-question

Based on the analysis in Chapter 5, and the discussion of the hypotheses, the second sub-question can be answered. Until 2017, Dutch newspapers constructed a discourse surrounding intersex that was based on the medical frame. Intersex was discussed as a medical problem, and as an issue that medical professionals had authority over. Since 2017, this discourse has started to change. Intersex organisations, like NNID, have attracted some standing with the media, and intersex is more often discussed from a human rights frame. This means that intersex issues are increasingly seen as a social issue, and intersex is regularly included in discourses about sex-, gender- and LGBTI issues. At the same time, medical professionals are still asked for their opinion about intersex issues and the male-female binary is still reproduced in Dutch newspapers. It can be concluded that Dutch newspapers construct discourses about intersex that use both a medical frame and a human rights frame, and since 2017 the human rights frame is being used more often compared to the medical frame.

### 6.1.6. Answer to the main question

The main question of this research is: *to what extent did the intersex movement in the Netherlands influence the discourses about intersex in the Dutch media?* The answer is that the intersex movement in the Netherlands has been able to influence the discourses in the Dutch media to a certain extent. The human rights frame has become more visible in the public discourse since 2017, in comparison to the medical frame. On the one hand, NNID has been able to generate some standing with the media, which enabled them to produce a human rights frame in Dutch newspapers. In addition, the alliance between NNID and the LGBTI organisations has also influenced the inclusion of intersex in LGBTI discourses. On the other hand, the patient organisations have not generated standing with the media and have thus not been able to influence the public discourse. Furthermore, as mentioned earlier, it is unclear to what extent the intersex movement has influenced the general change in the public discourse that has made sex-, gender- and LGBTI-issues more visible or whether these discourses have influenced the framing of intersex.

### 6.2. Research implications

This research contributes to the existing knowledge on the impact of the intersex movement in the Netherlands in three ways. First, the results show that when NNID is directly or indirectly quoted, they can express their preferred frame about intersex issues. This demonstrates that it matters *who* is speaking. This confirms the importance for social movements to have and be able to attract standing with the media to successfully influence the public discourse. These findings are relevant because it shows that social movements can dispute dominant frames in the public discourse

by having standing. For NNID, this means that they have to keep trying to gain standing with the media to make sure that their preferred frame is present in media discourses about intersex issues.

Second, this research demonstrates the importance of social movement coalitions, as this has had the biggest impact on the visibility of intersex in the public discourse, namely the inclusion of the 'I' in LGBTI. It indicates that the success of social movements relies upon their capability to form movement coalitions and build a network. For NNID, this entails that the organisation has to keep up their efforts to work together with other relevant organisations. Moreover, although there is some discussion about whether or not the 'I' fits with the other letters of the LGBT community, this research shows that it is extremely important for the visibility of the intersex community to be included in this abbreviation.

The third contribution of this research is about how it has shown NNID that their work has influenced the public discourse, especially since 2017, but that they have to actively keep trying to raise awareness for their issues. The organisation runs the risk of being overshadowed by other LGBTI organisations, as they have had more time to attract resources and have gained more standing. Therefore, NNID has to keep working on building constructive relationships with journalists and make use of the resources available to them to attract standing and articulate the human rights frame in the media about intersex issues.

### 6.3. Limitations

As with every research, some limitations have to be discussed. First of all, this research involved a CDA of which the interpretation of the results is one of the most important elements. The interpretation of the researcher can influence the findings and thereby the answer to the research question. An important part of qualitative research is reflexivity: the researcher has to be aware of her ideas and values during the interpretation of the results. By critically reflecting on the interpretation of the results, while being aware of her reference frame, bias can be avoided as much as possible.

In addition, to avoid potential bias, this research made use of a strict coding scheme of which every step has been described in Chapter 3. Moreover, the aspects that were being studied were clear beforehand: visibility indicated the number of articles per year. The second aspect was standing, which meant writing down when someone was directly or indirectly quoted, which also leaves little room for interpretation. The third aspect is the most interpretable: framing. However, to avoid creating biased frames while reading the articles, the frames were established beforehand. During the analysis, the articles were continuously compared to the earlier formulated frames, which made it clear which framework was being used to interpret the results. This also enhanced the transparency and reliability of this research.

Another limitation of this research is that the aspect of standing cannot measure what processes may have influenced a journalist while writing an article. It only looks at who is visibly quoted in an article. Consequently, the researcher does not know who else has been able to influence the framing 'behind-the-scenes', besides those who are quoted. At the same time, those organisations or people that are quoted are perceived as relevant actors, otherwise, they would not have been included in the article. Therefore, 'having



standing' gives a good indication of whom the media views as an expert regarding a specific issue, and who directly impacts the public discourse.

#### 6.4. Recommendations

Due to the limitations of this research, further research is recommended. First, to overcome the possible limitation of only looking at 'standing', researchers could take a closer look at the processes before, during and after a news article is published. This could reveal to what extent the intersex movement influences the public discourse from 'behind-the-scenes'. To investigate this, interviews with journalists and employees of intersex organisations could be conducted.

Second, this research only investigated newspapers, but the public discourse in the media is also influenced by social media, television- and radio programmes. Further research could look at the discourses about intersex on social media and in television- and radio programmes. More media outlets provide information about intersex discourses that could be compared to the results of this research, to see whether discourses on social media and in television- and radio programmes have gone through the same development as in newspapers.

Third, to discover whether the intersex movement has had an impact on policy-making or policy decisions, researchers could investigate policies and policy changes regarding intersex. An analysis of the development of certain policies could demonstrate if intersex organisations are being listened to, by looking at whether for example specific ideas that they mention in the media are discussed in parliamentary debates. Interviews with employees of intersex organisations and parliamentary members could help to answer these questions.

It is relevant to know what strategies make social movements successful in influencing the public discourse, both for social movements to know what strategies are useful and for policy-makers, to be aware of the strategies social movements use to influence policy-making processes. The intersex movement still has a long way to go in making intersex more visible in public discourse as a social issue, but this research has shown that their efforts are paying off and that the human rights frame is becoming more regularly used in the public discourse.

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### English

For more publications in English, see:  
More information on intersex in English:  
Database on intersex rights in English:

[thisisintersex.org/publications](https://thisisintersex.org/publications)  
[thisisintersex.org](https://thisisintersex.org)  
[intersexrights.org](https://intersexrights.org)

### Nederlands

Voor publicaties in het Nederlands zie:  
Informatie over intersekse in het Nederlands:  
Informatie over Stichting NNID:

[seksediversiteit.nl/publicaties](https://seksediversiteit.nl/publicaties)  
[seksediversiteit.nl](https://seksediversiteit.nl)  
[nnid.nl](https://nnid.nl)





***The intersex movement  
still has  
a long way to go  
in making intersex  
more visible  
in public discourse  
as a social issue,  
but this research has shown  
that their efforts  
are paying off  
and that the  
human rights frame  
is becoming  
more regularly used  
in the public discourse.***