

## Mapping the terrain of disability and sexuality: from policy to practice

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### Abstract

This paper is based on a lecture held in Nagoya, Japan as part of a seminar on issues relating to disabled women, sexuality and sexual and reproductive health and rights (SRHR). I present preliminary results from the research project *Sexual Citizenship and Disability: Implications for Theory, Practice and Policy*, which focuses on sexual rights for people with mobility impairments. The data comprises policy analysis and interviews with organizations working with sexuality and disability issues in Sweden, the Netherlands, England and Australia. While this paper has a somewhat broader approach than the seminar in Nagoya, the themes are nevertheless relevant to disabled women. I give examples of policies and work by organizations around disabled women's rights, sex education, sexual and reproductive health and rights (SRHR), and different kinds of sexual support services. The research demonstrates the variability of how sexual rights are understood and their culturally-specific nature. It shows how the personal is indeed political: states' different policy approaches change the outcomes for disabled people in terms of support to explore and express their sexualities. The role of the disability movement, and which issues it takes up, is also influenced by the policy landscape. This highlights how some of the organizations inadvertently adapt to what is deemed as 'policy-relevant' and how sexual rights are often less a priority than other rights – especially in times of austerity.

**Keywords:** disability; sexual health; sexual rights; policy; disability movement

### Introduction: Understanding sexuality and disability

Few people would argue against the notion that everybody has the right to express their sexuality without being discriminated against, so long as it does not hurt another person. But there is a problem with such an abstract concept: it conceals one of the major dilemmas in the rhetoric of rights, namely how they are to be implemented in practice and whose responsibility it is. In other words, a power dimension which is central to understanding why sexuality and disability is hidden. In this paper, I will give examples from disability and sexuality organisations' work in different countries which will illuminate these power dimensions as well as their contextual conditions (political, cultural, etc.).

Before I begin discussing the research findings I want to lay out the groundwork on the concept of sexuality. Because when we talk about sexuality we may in fact mean different things, such as sexual orientation, sexual identity, sexual and reproductive health and rights (SRHR), or sexual activity. Indeed, sexuality is a broad and complex concept, defined by the World Health Organisation as 'a central part of being human', that develops throughout the life course, and is an interplay of biological, psychological, social, economic, political, cultural, legal, historical and religious aspects (WHO 2018). Or as it has been defined sociologically: 'wherever two persons are together sexually society is present as a third party' (Helmus 2004, 107).

And it is here that the power dimension comes into play, with social structures and norms influencing sexuality, deeming certain sexual identities and activities 'normal' and others 'abnormal' (Rubin 1984). What is considered 'normal' forms the basis for state institutions and social norms, which subsequently influence the conditions for relationships, identities and reproduction, while the 'abnormal' is associated with risks that need to be controlled (Emens 2009). This system contributes to our socialisation from childhood and throughout the life course whereby we learn the norms around when, where, why, how and with whom it is acceptable to express our sexuality (Gagnon and Simon 2005). The biological and physiological conditions that the human body has to experience and express sexuality are influenced by societal and cultural norms about how they *should* be experienced and expressed (Weeks 2010).

When it comes to norms around disability and sexuality specifically, previous research shows that people with mobility impairments are often de-gendered, de-sexualised and deemed unattractive (Liddiard

2017; Shakespeare, Gillespie-Sells, and Davies 1996). Even worse, such views risk being internalised and form part of one's self-identification in a culture where there is a lack of depictions of the existing bodily and sexual diversity – a self-fulfilling prophecy (Malmberg 2012; Shuttleworth 2012). Because although an impairment can result in reduced sensations, paralysis or even pain, which in turn may affect one's sexuality to various extent, the possibility to experience and express sexual desire persists – although perhaps in other ways than the perceived 'normal'.

In other words, the idea of disability and what is considered a 'normal' body is closely related to the idea of 'normal sexuality'. The sexual, and even more so, the 'sexy' body relies on ideas of being healthy, independent and fit – characteristics which are often the opposite to how disabled people are viewed. These notions are especially problematic for disabled people who are also reliant on support services in their daily lives and who may need these in their sexual lives as well. Additionally, depending on their type and level of impairment, their gender, ethnicity, age, and so on, disabled people may experience sexual opportunities differently. An intersectional lens is necessary.

To sum up, we need to see the interplay of individual, social and political dimensions and how they impact upon disabled people's sexual rights. Sexual rights are part of human rights, but they will have no true meaning for disabled people unless they are implemented in practice – in a way that takes disabled people's lived experiences into account. Sexual rights can also be understood within the framework of citizenship, which further politicises the issues. Diane Richardson (2000) conceptualises sexual citizenship as a collection of sexual rights: the right to express one's desired sexual practice, the right to define one's sexual identity and the right to have it acknowledged by state institutions. Although sexual rights and sexual citizenship theory rarely acknowledge disabled people, they offer a relevant starting point for looking at how sexuality can be included as a dimension in rights and justice claims (Liddiard 2017).

## Data and methodology

This research primarily builds on fieldwork conducted in England, the Netherlands and New South Wales within the framework of the project *Sexual Citizenship and Disability: Implications for Theory, Practice and Policy* (Bahner 2018).<sup>1</sup> It includes online materials, policy analysis, interviews with representatives of organizations working with sexuality and disability issues, and in some cases interviews with policymakers. I also present some parts of my previous work in Sweden (Bahner 2015b).

Interviews were conducted using a semi-structured approach (Kvale and Brinkmann 2009). Participants were anonymised with regards to their names but not their organizational affiliation. They were informed about procedures and principles regarding informed consent, and data management. Interviews were transcribed verbatim and all research data was imported into NVivo 11 software for use in the qualitative analysis (Patton 2002). The study was granted ethical approval by the ESSL, Environment and LUBS Faculty Research Ethics Committee, University of Leeds (AREA 15-078).

My analysis departs from the "What's the Problem Represented to be?" (WPR) approach:

By asking how "problems" are represented or constituted in policies, it becomes possible to probe underlying assumptions that render these representations intelligible and the implications that follow for how lives are imagined and lived. (Bacchi and Goodwin 2016, 6)

In other words, I am not only interested in the discursive conceptualizations of the issues around sexuality and disability, but also how these discourses influence policies, organizational priorities and more importantly, the effects on disabled people's sexual opportunities. I use this approach in my analysis of policies, interviews, information and materials provided by organizations – all relevant data that articulate a certain way of understanding the 'problem' of sexuality and disability.

## Sexuality and disability: policy context

This first part of this section presents my policy findings. I start with introducing international policies on sexuality and disability respectively. I suggest that the existing international declarations on sexuality-related issues from recognized organizations and the UN Convention on the Rights of Persons with

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<sup>1</sup> In the UK and Australia different states have different legislation and policies. Therefore, the states of England and New South Wales have been chosen as case studies.

Disabilities (CRPD) offer a useful starting point for developing local policies, be it on national, regional or organizational level. In part two I move on to the national policy contexts under study.

### International policies

Research and population studies from global organisations have shown that disabled people often lack access and resources to have their sexual health and reproductive rights (SRHR) met sufficiently (WHO and UNFPA 2009; UNFPA 2018b). Disabled women's and girls' needs have been particularly explored (UN 2017). Nevertheless, there are no specific policies dealing with disability and sexuality, however as the following sections will show, disability and sexuality policies respectively can offer useful frameworks for developing specialized programs.

### Sexuality policy

It is interesting to note that 'the first wave of human rights as applied to sexuality' emphasised issues relating to family planning and women's rights to freedom from violence and discrimination (Miami 2015, e48). In other words, there has been a clear gender bias as well as a leaning towards health-related issues in the field of SRHR and sex education. Only later did the concept of sexual health become reformulated to not only relate to reproductive health but also include notions of sexual well-being and the right to pleasure (ibid.). This development can be seen in the definition of sexual health provided by the World Health Organization (2018):

Sexual health is a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.

In other words, there is a distinction between sexual health and sexuality. The definition of sexuality reads:

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. (...). Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors. (WHO 2018)

While originally developed within the framework of United Nations (UN) and WHO conferences, civil society organizations such as the International Planned Parenthood Federation (IPPF) and the World Association for Sexual Health (WAS) have become influential actors in the conceptualization of sexuality, sexual health and sexual rights. In their Declaration of Sexual Rights, WAS provides the following wording as specifically related to sexual activity and pleasure:

Everybody has the right to the highest attainable level of health and wellbeing in relation to sexuality, including the possibility of pleasurable, satisfying, and safe sexual experiences. (WAS 2014, Statement 7)

In the last decade, updated formulations of sexual health and rights have become more politicized by being more clearly connected to human rights and the promotion of civil liberties. Furthermore, the concept has been broadened by including issues relating to Lesbian, Gay, Bisexual and Trans (LGBT) populations (Miami 2015).

Another important topic, especially for young people, is sexuality and relationship education. The United Nations Population Fund (UNFPA) provides the following broad definition of comprehensive sexuality education (CSE):

Comprehensive sexuality education (CSE) is a curriculum-based process of teaching and learning about the cognitive, emotional, physical and social aspects of sexuality. It aims to equip children and young people with knowledge, skills, attitudes and values that will empower them to: realize their health, well-being and dignity; develop respectful social and sexual relationships; consider how their choices affect their own well-being and that of others; and, understand and ensure the protection of their rights throughout their lives. (UNFPA 2018a, 16)

In the guidance for teaching sexuality education, the UNFPA suggests the inclusion of ‘eight key concepts which are equally important, mutually reinforcing and intended to be taught alongside one another’: relationships; values, rights, culture and sexuality; understanding gender; violence and staying safe; skills for health and well-being; the human body and development; sexuality and sexual behaviour; and sexual and reproductive health (ibid., 35). In other words, in the same way as sexual health and sexuality are broad subjects, so is sex education.

### *Disability policy*

The UN Convention on the Rights of Persons with Disabilities (CRPD) is a central piece of international disability policy. It describes how human rights, which are already enshrined in other conventions, apply to the specific situation of disabled people. In the first article the general aim of the Convention is described: to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities’ (United Nations 2006). There is no specific article on sexual rights, however, there are several other articles that can be related to sexuality indirectly:

- Article 5 Equality and non-discrimination
- Article 8 Awareness-raising. Includes: (a) ‘to foster respect for the rights and dignity of persons with disabilities’ and (b) to combat stereotypes and prejudices.
- Article 12 Equal recognition before the law
- Article 16 Freedom from exploitation, violence and abuse
- Article 17 Protecting the integrity of the person
- Article 19 Living independently and being included in the community
- Article 20 Personal mobility, and especially (d) which encourages production of mobility aids etcetera which take into account *all aspects of mobility* for disabled people.
- Article 21 Freedom of expression and opinion, and *access to information*
- Article 22 Respect for privacy
- Article 23 Respect for home and the family. Specifically encourages ‘effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others’. The right to marry and found a family (a), to decide freely about children and the right to information and education concerning reproductive issues (b), and the right to retain one’s fertility (c).
- Article 24 Education (which ought to include sexuality education).
- Article 25 Health, where (a) specifically mentions the right to sexual and reproductive health.
- Additionally, Articles 6 and 7 concern disabled women and children respectively.

If we regard sexuality in the broad sense suggested by international declarations, then all of these articles are relevant to disabled people being able to develop sexual well-being, be it through education, mobility or simply being recognized as sexual in culture.

It is interesting to note that sexual rights, as formulated by WAS to specifically include the right to pleasure, does not occur in the CRPD. Analyses of the drafting process of the convention show that the Ad Hoc Committee negotiations resulted in a ‘far less explicit and affirmative’ Article 23 than what was initially discussed (Schaaf 2011, 113). The draft presented to the Committee on the fifth session read as follows:

That persons with disabilities are not denied the equal opportunity to [experience their sexuality,] (3) have sexual and other intimate relationships [through a legal marriage] and experience parenthood [in accordance with the national laws, customs and traditions in each country]. (Schaaf 2011, Annex 1)

This draft is also similar to how sexuality is framed in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993):

#### **Rule 9. Family life and personal integrity**

Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood.

(...)

States should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities (...). The media should be encouraged to play an important role in removing such negative attitudes.

In other words, it seems as though earlier declarations on disability included more outspoken statements on sexuality, thereby providing a more holistic understanding of sexual rights. Notwithstanding, the CRPD is still a useful tool for policy development, especially if combined with declarations on sexuality.

### Local policy contexts

Although there are international standards for disability and sexuality policy, how states choose to implement them varies significantly. In the following sections, the central policies in Sweden, England, the Netherlands and New South Wales will be presented. Since my research focus is on sexual support I have looked most closely on those relating to Independent Living (IL).

#### Sweden

Swedish disability policy has long been hailed internationally as a gold standard, especially with regards to implementation of Independent Living (IL) principles (Anderberg 2009). Even compared to the other Nordic countries, Sweden has the most comprehensive law; the ‘Act concerning support and service for persons with certain functional impairments’ [Lag om stöd och service till vissa funktionshindrade (LSS)] (Askheim, Bengtsson, and Richter Bjelke 2014). Through LSS, eligible people with ‘extensive disabilities’ are entitled to personal assistance, among other services, with the aim of ‘living a life like others’ under good living conditions and, furthermore, to make it possible for them to participate on equal terms in society.

However, in recent years, there have been efforts by the government to review the law to cut costs in personal assistance services, resulting in many people having their applications rejected and losing their assistance partly or altogether. A recent analysis indicates that ‘a major reason for the reviews was due to an unprecedented rise in demand for personal assistance, which far exceeded the government’s initial expectations when the law was implemented’ (Brennan et al. 2016, 7). In other words, the central aims of LSS are being eroded on economic grounds, which can be said to violate Sweden’s obligations under the CRPD (CRPD Committee 2014).

Sexuality is not mentioned in the LSS or any other disability services policy. While the National Board for Health and Welfare offers advisory guidelines to the social services in a range of issues, they have not issued anything related to sexuality. Therefore, many service providers are insecure whether it is legitimate to offer sexual support (Bahner 2015a, 2015b). In an effort to prevent sexual abuse, raise the knowledge about sexuality and disability among staff, and to provide professional and ethical guidelines, some municipalities have published their own policies and offered training (cf. Olsson 2015).

With regards to sexual health policy, the Public Health Agency is currently undertaking a population study to explore sexual experiences and needs, which will guide the development of a new policy. To what extent it will include disabled people’s needs is not yet known.

#### England

The UK was recently reviewed by the CRPD Committee (2017), which expressed grave concerns over the effects that the government’s cuts to disability services have had on disabled people’s lives (see also a recent report from the Equality and Human Rights Commission, EHRC 2017). Similarly to Sweden, there have been reviews to disability benefits regulations, resulting in reduced eligibility and people losing their support. Meanwhile, the disability policy *Fulfilling Potential* has not been updated since 2015 (Office for Disability Issues 2018), and a recent interview with a government official indicated that it was in fact scrapped with no evident plan to renew it or develop a new one (Pring 2018).

From a sexuality perspective, *Fulfilling Potential* did not offer much potential in terms of highlighting sexual rights. If we instead turn to *A Framework for Sexual Health Improvement in England* this policy only mentions ‘people with learning disabilities’ (Department of Health 2013). The issues discussed are the need for better and more accessible sexuality education, vulnerability to sexual abuse, abortion counselling and the potential need for extra support in decision making. In other words, the focus is on traditional SRHR issues rather than being based on a broader understanding of sexuality and sexual rights.

Nevertheless, the legal framework for disability and sexuality holds potential. Disabled people are protected by the Human Rights Act (1998), the Equality Act (2010) and the Care Act (2014). Sexual rights

are mentioned somewhat abstractly as ‘the right to respect for private and family life’ in the Human Rights Act (Article 8). The Care Act on the other hand provides a framework for ensuring disabled people well-being in the area of ‘domestic, family and personal relationships’ (Care Act §1), which could possibly include sexual life. The Equality Act includes a duty to make ‘reasonable adjustments’ for disabled people if they are disadvantaged in comparison to non-disabled people.

Policy approaches focus more on safeguarding and ‘the prevention of risk rather than the enabling of rights’, resulting in a lack of support for sexual expression (de Than 2015, 86). However, the British Institute of Human Rights (2018) offers a case study example of a disabled gay man being denied support to visit a pub as a breach of human rights on the grounds of his right to respect for private life (Article 8) and his right not to be discriminated against on grounds of sexual orientation (Article 14). While such a case has not been tried in Court, it does offer a starting point for working with sexual rights in practice.

### *The Netherlands*

Dutch disability policy stands out from the other countries under study. Firstly, the Netherlands was rather late in signing the CRPD in 2016. The body responsible for its implementation is the Ministry of Health, Welfare and Sport (VGN). They are currently developing the strategy that will become the new framework for disability policy, which has not existed before. Instead, the policies relating to disabled people have been related to unemployment, sickness and disability benefit programs (Berkel 2013). Similar to the UK and Sweden, welfare reforms have aimed at reducing the generosity of benefits by stricter and more medicalized eligibility criteria (de Jong 2012), making ‘the welfare/workfare divide now evident in Dutch social protection’ (Yerkes and van der Veen 2011, 434). The Netherlands Institute for Human Rights (2017), which supervises the government’s compliance with the CRPD, hopes that its implementation will further a more social and rights-based understanding of disability and disabled people.

Rutgers, an international centre of expertise on sexual and reproductive health and rights based in the Netherlands, is the major actor in research, policy development and implementation on all issues relating to SRHR. They are partly funded by the VGN to, among other things, ‘support comprehensive sexuality education in schools, the sexual and reproductive health of vulnerable people and the reintegration of people who have committed acts of sexual violence’ (Rutgers 2018b). With regards to disability, their focus lies primarily on youth with intellectual impairments, for whom they provide sex education programs in special schools and conduct research on relevant topics. There have been a few temporary projects aimed at youth with mobility impairments (see below).

A group of sexologists working in the field of rehabilitation have also been vocal in furthering the sexual rights of disabled and chronically ill people, especially with regards to rights to financial compensation for sexological rehabilitation, sexual services, privacy in residential homes, and increased training on sexuality for professionals working with disabled people (focus group interview). People from this group, as well as from Rutgers and disability organizations, are currently part of an advisory group on sexuality issues to work with the VGN in the CRPD implementation process. The group was set up following a motion in the Dutch parliament urging the government to include sexual rights in the implementation process (Rijksoverheid 2018). However, the group seems to have achieved little success in terms of including sexuality in the disability strategy (interview), and so it is unclear how the decision on the motion’s aims will be realized.

### *New South Wales, Australia*

In Australia the *National Disability Strategy 2010-2020* provides a framework for disability rights. It does not mention sexual rights, although it points to it as an area of future improvement, at least when it comes to accessible sexual health care (Commonwealth of Australia 2011, 64). In contrast, the *Disability Inclusion Act* states sexual rights as one of the core principles of disability rights: ‘People with disability have the right to realise their physical, social, sexual, reproductive, emotional and intellectual capacities’ (New South Wales Government 2014, General principles #4).

On this basis, the NSW government’s Department of Family and Community Services has issued a set of guidelines for service providers on how to support disabled service users with sexual education and information, sexual expression, and sexual activity (2016). Since commercial sex services are legal in NSW, they present a legitimate alternative for sexual support, for example as provided by the charity Touching Base (see below). However, more intimate types of sexual support, such as staff assisting disabled service users during sexual activity, are not allowed. In other words, there is still a space where

some disabled people's needs are not adequately met (interviews with Northcott, a disability service provider, and the NSW Department of Family and Community Services).

Currently, there are many changes underway in Australian disability services due to the implementation of the National Disability Insurance Scheme (NDIS). The NDIS Act (2013) is a response to the CRPD in an effort to nationalize disability services. It aims to 'support the independence and social and economic participation of people with disability' (3 c), by '[providing] reasonable and necessary supports' (3 d) that 'represent value for money' (34 c). Following the wider personalization agenda, this compulsory scheme is set up to allow disabled people to purchase the services or their choosing through individual funding packages (Carey et al. 2018).

The NDIS Act (2013) does not mention sexuality, however, the NDIA that is responsible for implementing the scheme mentions it as part of the aim 'Promoting independence'. Within the 'Relationships' domain, the 'independence measure' to 'engage in safe sex' is exemplified, with the accompanying strategy to 'provide people with training and support in sexual health' (NDIA 2018c). Furthermore, in their 'advice on reasonable and necessary support across the lifespan: an ordinary life for people with disability', it is mentioned that 'becoming sexually active' is a 'key feature of the life stage' for young adults 16-25 years. For adults it is described as a key feature to 'have relationships including sexual partners' (NDIA 2018a).

Worries have arisen with disabled people, their organizations and service providers as to how sexual support services will be handled. A recent statement from the the NDIA said 'The NDIA does not cover sexual services, sexual therapy or sex workers', however, 'A plan may include psychological counselling or physical therapy to help someone understand and overcome a physical impediment to intercourse' (NDIA 2018b). In other words, it is unclear how the described 'key features of the life stage' in the relationships domain will actually be implemented in practice.

### Disabled people's organisations and sexual rights advocacy

In the landmark book *The Sexual Politics of Disability – Unmet Desires* (Shakespeare, Gillespie-Sells, and Davies 1996) British disabled people's experiences of sexuality, sex and relationships were explored. It showed that the topic of sexuality was not commonly discussed within the disabled people's movement, as it was seen by many as less relevant than more public issues such as accessibility, housing and work. Similarly, in the US, there were experiences of difficulty raising these issues:

Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing – discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction. (Finger 1992, no page number)

Perhaps these experiences are both influenced by and influential in creating a policy context where disability and sexuality are not often discussed. The struggle has been similar in the women's movement, where issues relating to the more intimate and private aspects of life have been deemed apolitical – the male-dominated domains of work and public life being deemed most relevant (Lister 2003).

Nevertheless, there are examples of sexual rights advocacy carried out by disabled people's organizations, as well as other types of organizations. In the following sections, four organization types will be discussed: disabled women's organizations; disability organizations focusing on sexuality information and advice; organizations focusing on disability and sex work; and sexual care organizations for disabled and elderly people. Additionally, I will give example of temporary projects in the area of sexuality and disability, which are ran by sexual health organizations primarily, but also disability organizations in some cases.

### Disabled women's organisations

In Sweden, the UK and Australia there are disabled women's organizations working in similar ways and which are all connected to the international women's rights movement as well as the disabled people's movement. The three organizations I visited are all run by and for disabled women with a variety of impairments. A core component of their work is to represent disabled women's interests in state committees on gender or disability issues, in national women's organizations and in disabled people's organizations. They also submit responses to national and international reports on related issues, for example to the UN Special Rapporteur on the Rights of Persons with Disabilities who conducted a global

study on the sexual and reproductive health and rights of girls with disabilities, and to the committees reviewing the countries' work with implementing the CRPD and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). There are no such organizations in the Netherlands (Jacqueline Kool, personal communication, September 26, 2018).

### *FQ Forum – Women and Disability in Sweden*

FQ work for the empowerment of disabled women. They started as a project about disabled women's experiences of living in a disabling society and held seminars and published reports aiming to enhance the knowledge in disability organizations as well as in society more broadly about these issues. Another important part was to create a safe space for disabled women to share their experiences. Today, FQ's focuses on all areas of public, political, cultural and private life (education, work, economy, parenthood and sexuality, social services, culture, health, care and rehabilitation, violence and abuse, immigrant disabled women, and research).

With regards to sexuality, FQ works for 'the recognition of disabled women as worthy partners and parents, and for a self-evident right to their own sexuality' by removing 'the attitudinal, social, practical and economical barriers that prevent that' (FQ 2002). In the last year there have been two debates that engaged much of FQ's work: #MeToo and the Swedish government's cut-backs in disability services. In both cases, FQ have campaigned to make disabled women's needs visible.

A recent organizational and ideological change in FQ was to welcome disabled trans women as members. The decision was based on the understanding that anyone who identifies as a disabled woman should be seen as a disabled woman – it is nobody else's decision what another person identifies as, be it about gender identity or disability (FQ 2018). In their recently published *20 years of struggle for gender equality and social equality* (Wermeling 2017) this decision is described as something that made many members proud, while it has also resulted in some leaving the organization.

In FQ's collaboration with non-disabled women's organizations there has been tensions around one specific aspect that divide the two movements. While disabled women struggle for recognition as gendered and sexual beings, many non-disabled women's organizations struggle for women to be seen as more than just sex objects (ibid., 27f). But overall, FQ feels that the women's movements share the understanding of the intersectional nature of women's identities and lived experiences, including aspects of ethnicity, age, economy, sexuality, impairment, and so on – something that has been less successfully argued within the disability movement (ibid.).

### *Sisters of Frida*

Sisters of Frida (SoF) in the UK work in similar ways to FQ although their organization is more recently established. It evolved from informal meetings of disabled women into a cross-impairment community interest company in 2014; for all who identify as women, including trans women. They call themselves 'an experimental collective of disabled women' that offers peer support and a safe space to meet and share experiences (Sisters of Frida 2018b).

Rather than primarily creating projects and events they join other disabled people's and organizations' events, actions and projects. They often participating in panels on disabled women's issues. Intersectionality is a core component of their work and the membership constitutes a diversity of impairments, ethnicities, sexualities, ages, and so on. The cultural differences between Sweden and the UK becomes evident when looking at the steering committees as well as the membership of FQ and SoF, where the latter show a more diverse community.

Just like FQ, SoF campaign on a wide array of issues that impact upon disabled women's lives. On their website they mention employment and pay, violence and abuse, health and medical care, mental health, and public life. Besides public campaigning on these issues they do workshops and courses aimed at the membership, when they find the appropriate funding for it. For example, following the wishes from some members they arranged a series of sexuality workshops exploring 'what sex means for us as disabled women, non-normative sex, positive self-image, exploring sex alone and sex with others' (Sisters of Frida 2018a).

### *Women with Disabilities Australia*

WWDA has a similar history to FQ and SoF in that it started with a group of disabled women who felt a need for a women-only disability organization. At the time, many disabled women who were active in the disability movement felt that the existing organizations were dominated by disabled men and that there

was a lack of recognition of the issues facing disabled women (WWDA 2018a). WWDA initially began as a women's network within Disabled People's International Australia (DPIA) in 1985. Following continued failures by DPIA to respond to the needs and concerns raised by the disabled women's network, as well as refusal to provide adequate resourcing to them, the women decided to establish an independent women-led organization. This finally happened in 1995 after some years of struggles to secure funding. Issues around violence, forced sterilization and sexual and reproductive health and rights have been central to their work, as has intersectional perspectives.

WWDA describe the organization as 'unique, in that it operates as a national disability organisation; a national women's organisation; and a national human rights organisation' (ibid.). Like FQ and SoF their aim is to raise awareness on issues facing disabled women, raising from sexual and reproductive rights to employment and housing. Their strategies include lobbying, representation and education. However, they seem to work more broadly than FQ and SoF as they also work with research and policy development; project development and implementation; and quality improvement, strategic planning and program and project evaluation. WWDA's ability to do this kind of work is probably due to having more substantial and continuous funding, currently provided by the Australian Department of Social Services (DSS) on a three-year funding cycle (ibid.).

WWDA also has a youth network 'to specifically voice the needs and rights of young women and girls with disability' (WWDA Youth Network 2018b). The Youth Network has developed a comprehensive human rights toolkit which facilitate young women and girls to learn about their human rights in an accessible way. They have also written position statements on Violence, Decision-making, Participation, Sexual and reproductive rights, Work and education, Justice, and Young women and girls with disability (WWDA Youth Network 2018c). The Youth Network also provides online resources on a wide range of topics, including Gender & sexuality issues and Sexual & reproductive health. In this way, young women and girls can find information that is relevant to their experiences of impairment and disability.

#### Disability organizations providing sexuality information and advice

Although the disabled women's organisations are important actors in raising awareness of and promoting sexual rights, their work includes all other issues in life as well. In Australia, the Netherlands and the UK there are examples of organizations working specifically with issues around disability and sexuality. In Sweden no such organizations exist, however, some disability organizations as well as sexuality organizations have run temporary projects on the subject (see later sections).

#### *Enhance the UK*

Enhance the UK is a charity run by disabled people, founded in 2009. Their work focuses on the needs of people with physical and sensory impairments. They offer disability awareness training, accessibility audits, run campaigns and do policy advocacy. One of their primary focus areas is sexuality. #UndressingDisability is a social media campaign and a photo book launched in 2015 with the aim to 'give disabled people the tools and the resources to feel sexually confident and comfortable' (interview, Enhance the UK). The campaign also includes advocacy work aiming to raise standards in sex and relationship education, and among professionals, service providers and families. Their website offers free relationship and sex resources, and hosts the *The Love Lounge*, an online Q&A site where answers are provided by a disabled man and woman (Enhance the UK 2018).

#### *Sex with a Difference (SWAD)*

SWAD in the UK started with a disabled woman's efforts to get support from her local council around 'the physical side of things' with regards to sex and relationships (interview, SWAD). But because neither they nor the local Independent Living Centre (ILC) could offer any help, she decided to take matters into her own hands. What first started out as a couple of informal workshops in the ILC turned into a website and a phone number which people could call to get advice, and eventually a company (SWAD 2018). SWAD arranges training courses, gives talks and offers personal advice to disabled people who have been unsuccessful in getting help from their social workers, occupational therapists or other professionals – who often lack the adequate education to do so. SWAD also works for policy change, mainly in the area of including sexuality and disability in relevant training programmes and in care planning and assessment of service users' needs.

### *The Handicap and Sexuality Foundation*

The Handicap and Sexuality Foundation in the Netherlands was formed in 1997 to facilitate empowerment and self-development among disabled and chronically ill people (Stichting Handicap & Seksualiteit 2018). They offer information, counselling and referrals to individuals in need of advice concerning sexual problems, as well as training to care providers and informal caregivers about disability and sexuality. Their aim is essentially to combat the taboo around sex and disability.

### *Disability and sex work*

Sex work is de-criminalized in the state of New South Wales, Australia, while in the UK and the Netherlands it is legalized under a specific regulatory framework. In the UK and New South Wales, organizations have been established that focus specifically on facilitating the access of disabled clients to sex workers. In the Netherlands, there is another organization type that offers ‘sex care’ services (see later section).

### *Touching Base Inc.*

Touching Base is a small charity based in Sydney, New South Wales. What started as ‘a series of conversations between a disability advocate and film maker, a sexual health professional and a sex worker’ soon turned into an organization (Touching Base 2018a). Touching Base works for the shared interests of disabled people and sex workers, facilitating the links between these two ‘marginalised communities’ (Touching Base 2018c). The management committee consists of disabled people, sex workers and representatives from the organizations Family Planning NSW (a sexual health service provider), People with Disability Australia, The Cerebral Palsy Alliance and Northcott (a disability service provider).

Touching Base works primarily with training programs, on the one hand aimed at disabled people, their carers and service providers, and on the other hand aimed at sex workers and other sex industry staff (Professional Disability Awareness Training). They also operate a ‘referral database of accessible commercial sex services premises and independent sex workers who are willing or have experience or training, to provide non-discriminatory services’ to disabled clients (Touching Base 2018b).

### *Outsiders Trust*

The Outsiders Trust in the UK has several sub-organisations focusing on different aspects of sexuality and disability issues. It all started in 1979 with the Outsiders Club, a dating club which also offers peer support and social activities (Outsiders 2018c). Today there is an online Clubhouse as well as social lunches around the country. In 2000 the website TLC (Tender Loving Care) was set up to facilitate disabled people in finding accessible sexual services, partnering with ‘reliable’ sex workers, therapists, and so on (TLC 2018). Three years later, the Sex & Disability Helpline was started, offering free personal advice (Outsiders 2018b). The Sexual Health and Disability Alliance (SHADA) was set up as a separate charity in 2005. It serves as a community for professionals for knowledge exchange and development (SHADA 2018). The members include sex workers, sex therapists, sex education professionals, academics, occupational therapists and many more. There is also a network of members in other countries on SHADA International. The Outsiders also run campaigns occasionally, for example, a demonstration on Westminster Bridge with the aim to ‘encourage society to view disabled people as sexual beings with the same desires and needs as everybody else’ (Outsiders 2018a).

### *Sex care and sexual assistance organizations*

In the Netherlands there are several organizations offering ‘sex care’ services to disabled, chronically ill and elderly people. The two main ones are SAR, an acronym that translates to the Foundation for Alternative Relationship Mediation, and FleksZorg – ‘when sex is care’. In Belgium, Aditi is an organization providing sexual assistance, similar to sex care. I interviewed them during my fieldwork in the Netherlands, and include them here despite Belgium not being one of my primary case studies, because Aditi’s work is an example of successful lobbying for policy changes.

### *Foundation for Alternative Relationship Mediation*

Stichting Alternatieve Relatie Bemiddeling (SAR) was started in 1982 by disabled people living in a residential community and care institution in Arnhem (SAR 2018). It is a non-profit company acting as a

mediation agency between disabled people and (for-profit) sexual service providers. Potential clients can submit information about their sexual needs and wishes, and SAR will then provide them with a contact to an appropriate service provider. Apart from referrals they also campaign to break the taboo around disability and sexuality, for example by giving lectures in care and educational institutions.

### *FleksZorg*

FleksZorg is a service provider of sex care services since 2005. Following an assessment of the potential client's sexual needs and wishes the appropriate sex carer is assigned. The agreement is recorded in the person's care file 'in order to prevent misunderstandings' (FleksZorg 2018). Apart from this they also advocate for disabled people's sexual rights and for a policy changes to recognize sex care as a legitimate service within the health care sector, which would then enable inclusion in the general reimbursement system.

FleksZorg also campaigns for a professionalization of sex care and their suggestions are to develop certified training courses, introduce a quality system for service providers and to promote research into sex care. Together with Rutgers and ActiZ, the trade association of organizations working in the field of care and support for elderly, chronically ill and young people, they have developed a manifesto on policy changes. One suggestion is for sexuality to be part of care plans, along with the usual information about medication use, diet and informal care (Rutgers 2018a).

### *Aditi vzw*

Aditi is a non-profit centre for advice, information and support aimed at disabled and elderly people and to their network. They have worked in the region of Flanders since 2008 and are a licensed healthcare provider offering training and policy development to service providers and staff, and sexual assistance services to disabled and elderly people. Aditi describes sexual assistance as 'different forms of support and assistance with intimate and sexual care issues', provided by 'professionally trained sexual assistants' within a 'clearly defined framework' departing from 'a care model' (Aditi 2017). Like sex care it can involve supporting disabled people 'to learn or improve their skills when it comes to interpersonal relationships, intimacy and intimate and/or sexual relationships' (EPSEAS 2018b).

At the moment, Aditi and its partners are waiting for the Flemish parliament to decide on their motion to introduce new regulations, which would allow and legitimize sexual assistance as a health care service (Vlaams Parlement 2018). Because of the upcoming elections, the discussions in the Commission for Welfare, Public Health and Family have been delayed (Steven De Weirdt, Aditi, personal communication, 20 September 2018). One of the main aims in the motion is to describe how sexual assistance differs from prostitution, because while national law does not prohibit neither sex purchase or selling, all third-party activities are illegal. Furthermore, municipal regulations vary greatly in aim and scope, where some are more or less regulatory (Reinschmidt 2016). The motion argues that a new legal framework is needed so that sexual assistance is separated from illegal activities related to the commercial sex industry.

Aditi is co-founder of the European Platform Sexual Assistance (EPSEAS), a network for sexual assistance organizations working for spreading the service model of sexual assistance in Europe. Their goals are to create a Sexual Assistance Training Program, unite and develop expertise in the area of sexuality and disability and to develop 'a manifesto of propositions and recommendations allowing to improve the legal framework adapted to quality and respectful Sexual Assistance for people with disabilities' (EPSEAS 2018a). They currently have members in Belgium, France, Spain, Italy, Switzerland, the Netherlands and the Czech Republic (cf. García-Santesmases Fernández, Vergés Bosch, and Almeda Samaranch 2017; Gammino, Faccio, and Cipolletta 2016).

### Projects around sexuality and disability

Besides organizations focusing their efforts on sexuality and disability specifically there are also disability organizations and sexual health organizations doing temporary projects on sexuality and disability in several of the countries under study. I will focus on projects targeted at people with mobility impairments, although it is evident that there are more projects in the field of intellectual impairments/learning disabilities.

### *Starting point: disability*

Several British disability charities have run projects and developed materials for the young people that they support.

Together for Short Lives works with children who have life-limiting and life-threatening conditions and their families. They did a project together with The Open University Sexuality Alliance, which resulted in *Talking about sex, sexuality and relationships: Guidance and Standards* (Blackburn et al. 2016). It is aimed at both the young people themselves to learn about their rights, and at staff and service providers to enhance their knowledge and supports. The Sexuality Alliance is currently discussing how to move forward with the project (interview, Together for Short Lives/The Sexuality Alliance).

Contact a Family supports parents of children with any type of disability or additional need. In 2005 they published three booklets on the theme *Growing up, sex and relationships*. It comprised one guide for young people, one to support parents and one for teachers working with sex and relationship education with young people who have physical and sensory impairments (Contact a Family 2018). Since then, the organization has not done any other work around sexuality.

Leonard Cheshire had the project *In Touch* with young disabled people living in their residential facilities. They did a project report, training resource and several films which are still available on their website (Leonard Cheshire 2018). Recently they also developed *Relationships, sex and you – a guide for people living in our housing with care services*, which helps residents learn about sexuality, their rights and what supports they can expect from staff. Furthermore, they have internal guidelines available to staff on ethical, legal and professional boundaries around sexual support. In other words, their sexuality work is entirely internal at the moment.

#EndTheAwkward was a social media campaign by Scope on sex and disability (among other topics), showcased by a number of humorous videos in which disabled people talk about issues they face (Scope 2018a). The campaign also included the *A to Z of sex and disability* online resource (Scope 2018b). Scope has since stopped working actively with sexuality issues and does not plan to do so in the near future, due to priorities in other policy areas (interview, Scope).

Trailblazers are a young campaigners' network within Muscular Dystrophy UK. The report *It's complicated* details the experiences of young disabled people with sex and relationships (Trailblazers 2018). The theme is one of many within their wider Independent Living campaign and they continue to advocate young disabled people's sexual rights.

In the Netherlands, Jacqueline Kool, a disabled woman, activist and co-founder of the Disability Studies in the Netherlands organizations, conducted a project which resulted in a theatre play and the book *Eros (un)limited: stories about limbs, life and lust* (Kool 2010). She interviewed 28 women with various physical impairments and conditions about their experiences of sexual identity, relationships and sex.

In Sweden, the Swedish Youth Federation of Mobility Impaired ran the project *Secrets known by many* between 2009 and 2012. The project included a series of workshops with members in local branches of the organization discussing the taboo around sexuality, relationships and sexual support needs of young disabled people who use personal assistance services. The experiences gathered in the workshops resulted in a handbook to personal assistance users and personal assistants (Svensk 2011). The Federation has not continued work around sexuality, although their local branch in Stockholm participates in a sexual health organization's project (see below).

### *Starting point: sexuality*

In England and in New South Wales there are similar organizations working in the field of sexual health; FP – the sexual health charity, and Family Planning New South Wales. However, none of them work specifically with the needs of people with physical or sensory impairments. Their work around disability is focused on people with learning disability/intellectual impairments, for example media campaigns aiming to challenge taboos and stereotypes, sex education, and training for staff.

In Sweden, the Swedish Association for Sexuality Education (RFSU) is the leading organization in the field of SRHR and sex education. Swedish teachers' education does not include sex education training, so many of them feel and indeed are ill-equipped to teach the subject. Therefore, many teachers turn to the local RFSU branch who can provide a sex education program for schools. It is only in recent years that RFSU has included disability perspectives in their work more consistently and with comprehensive influence from disabled people themselves. RFSU still do not advocate much specifically on disability rights, but they have a couple of projects on the local branch level in some cities.

These projects have mostly concerned people with intellectual impairments, but a few are focused on young people with physical or sensory impairments. *Teckna sex*, which can be translated to Sign sex, is a project to develop sex education materials in sign language and to introduce specially trained sex educators. *Sex i rörelse* means Sex in movement, which is about sex education for youth with mobility impairments, as well as about empowerment and development of practical resources for discovering one's body and facilitating sexual expression. This project is done in close collaboration with the Stockholm branch of the Swedish Youth Federation of Mobility Impaired.

In the Netherlands, Rutgers, the Dutch centre of expertise on SRHR, can be compared to the sexual health organizations mentioned above. Rutgers also mostly works around young people with intellectual impairments, but in 2012 they ran a project about young people with physical impairments or chronic illnesses. The *Totally Sexy* project resulted in magazines about sexuality aimed at the young disabled people, online resources and training guides for professionals, and a board game called SecZ Talk, which aims to facilitate conversations between staff and young disabled people about relations, intimacy and sexuality (van der Stege et al. 2016). At the moment, there are no specific projects on the topic, nevertheless, the online materials are still available (interview, Rutgers).

Another example from the Netherlands is the project *Everybody matters* by the Dutch Coalition on Disability and Development (DCDD) and Share-Net, the knowledge platform on SRHR. The project resulted in a publication with good practice examples of including disabled people in SRHR programs in developing countries (DCDD 2018). *Everybody matters* aims to not only show the hardships and barriers that disabled people face in realising their sexual health goals, but also providing concrete examples or successful solutions. The work was grounded on a twin-track approach to disability inclusion, meaning a combination of disability inclusion in 'mainstream' initiatives and disability-specific initiatives (ibid.).

## Discussion

Although my results are preliminary, the interplay between policy, culture and practice is evident. As shown in the following analyses of the case studies, certain aspects are visible in all or several contexts, while others are specific to each case. Thus, even though there are international conventions on disability rights and sexual rights, how they are understood and then implemented varies considerably – both with regards to policies and civil society organizations.

While Sweden has a seemingly generous disability services policy and a disability movement comprising many organizations, advocacy in sexual rights issues has not been prevalent. Instead, it is either disabled women's rights that are on the agenda, which do not necessarily include aspects of sexual support needs, or there are temporary projects on sexuality without much impact in the wider disability movement. The law prohibiting purchase of sex services has been cited as one reason for the lack of deeper engagement with non-commercial sexual support services, since the attitudes towards the former are largely negative and organizations do not wish to be associated with them (Kulick and Rydström 2015).

Nevertheless, the most recent project by RFSU in collaboration with the Stockholm branch of the Swedish Youth Federation of Mobility Impaired promises a change in direction. With the project including development of sex education as well as peer support, empowerment and knowledge about ways to pursue pleasure as a disabled young person, the more holistic concept of sexual rights has been manifest. However, support and legitimization are needed by the wider disability movement for adequate resource allocation and prioritization on the advocacy agenda – otherwise the work risks ending without further development and dissemination after the project period. In the current political climate of cutbacks to essential services, the attention inevitably risks going in other directions.

The Netherlands is an interesting comparison on several points: on the one hand, the relatively late development of more general disability policy, and the disability movement's smaller size and less impactful role; and on the other hand, the more comprehensive and state-funded work around sexuality, and the existence of a disability-specific 'sex care' service sector. Compared to Sweden, commercial sex services are legalized, which may be one reason for the more open debate about paid-for sexual support services. Nevertheless, there seems to be prevailing negative attitudes towards the commercial sex industry, leading to a wish by the sex care sector to define themselves as different (Reindl 2014). Like Aditi's pursuit in the Flemish parliament shows, there are legal implications to this as well.

The medicalization of disabled people's sexual support needs is a related Dutch dynamic. Unlike in the other countries, there is neither a Dutch disabled women's organization nor any major projects around sexuality and people with mobility impairments by the disability movement. Instead, the driving forces are medical professionals in rehabilitation sexology, sex care providers and Rutgers as an SRHR agency.

While the social model of disability is the taken-for-granted conceptualization in the UK, and to a large extent also in Sweden and Australia, where a human rights framework is emphasized, the Dutch understanding is based instead on a more bio-psycho-social model (interviews with disability organizations in England, the Netherlands and Australia).

When it comes to the impact of states' economic contexts, we see that the UK disability movement is hit hardest by austerity, leading the major disability organizations to focus their attention on countering further cutbacks and fighting for their rights to basic services. Yet there are numerous organizations working with sexuality issues in different ways. Although sexual support is not the main focus for most of them, they are important to disabled people struggling with their questions and support needs. With a recently-scrapped disability policy and an unsatisfactory sexual health policy (with regards to sexual support), the organizations active in the field would probably gain from collaborating and trying to achieve change together, be it in policy, practice or both.

The current implementation of the NDIS in Australia provides both opportunities and dangers for disabled service users. This nationalization of disability services aims to equalize service provision across the country. However, there is a risk that in places where services have worked well, for example through the development of local structures, these may have to be remodelled to fit the new national standards (interview, Family and Community Services). In NSW there is a strong collaboration between the government's Family and Community Services and the organizations working with sexuality and disability: Touching Base, Northcott and Family Planning NSW. It was in this collaboration that the state guidelines (2016) were produced as a useful guideline to service providers. The question is how they can be used in relation to the NDIA assessment guidelines, because although they provide a basis for including sexuality and relationships as a measure for independent living, the agency's statement that they do not cover 'sexual services, sexual therapy or sex workers' are not covered contributes to ambiguity (2018b).

In Sweden and England where national policies around sexuality and disability are largely missing, it has been civil society organizations that have taken the lead in providing support and services, often without state funding. While the organizations in England are largely funded by donations and sale of services, and many of them struggle with small resources due to cuts in state funding, the projects in Sweden are funded by the Swedish Inheritance Fund – a state agency. By failing to recognize disabled people's sexual support needs (either through policy or funding), it might seem that this issue is not considered policy-relevant. In Sweden, it is at least seen as relevant for civil society to engage with, by financing their projects – although temporarily. But similarly, it can be argued that disability organizations could prioritize their resources to better cater to women's and sexual rights. However, the current organizational separation of these issues may instead lead to an entrenchment of that division.

With regards to SRHR issues, there are several interesting aspects to consider. Firstly, it seems as though disability organizations in Sweden, England and Australia have largely left such issues to disabled women's organizations. Secondly, when looking at the specific SRHR issues that are being raised by disabled women's organizations they rarely include issues around sexual support. In other words, SRHR is conceptualized as women's issues, and as such, as belonging primarily to the sphere of reproduction, sexual abuse and victimization. While this focus is not surprising given a higher prevalence of violence against disabled women (Dowse et al. 2016), and the still ongoing forced sterilization or other types of control over disabled women's reproduction (Tilley et al 2012), these issues are also framed within a more traditional understanding of sexuality, which does not necessarily incorporate the right to sexual pleasure (Giami 2015). However, compared to many other women's organizations, as well as SRHR policies in general, disabled women's organizations seem more inclusive with regards to intersectional differences, especially towards trans women.

The question is whether it is the women's movement that has prompted such a focus on a traditional understanding of sexuality, or if it has come from policy, where SRHR issues have been deemed as women's issues. A recent report from UNFPA (2018b) gives a fresh perspective by including both disabled girls and boys, but they exclude non-binary and trans experiences (Slater and Liddiard 2018). Although the focus on women's rights is important and necessary in a world where women (particularly disabled women) are heavily discriminated against, the one-sided focus has led to a dearth of research about disabled boys, men's and other gender's sexualities and needs around SRHR. However, when issues around access to the sex industry are discussed, they often relate primarily to disabled men (Liddiard 2014). In other words, there is a need for intersectional development of disability and sexuality issues from several perspectives.

In conclusion, we can see that the field of disability and sexuality is broad – to say the least. Not only are there various ways of working with the multifaceted issues of sexuality and sexual rights, but there are

also contextual differences that impact upon how they are understood and engaged with. These variations are evident in policy discourse as well as in civil society. While my research comprises a limited set of case studies, the distinctions between them are telling: how disability rights and sexual rights are interlinked depends on the surrounding culture, politics and history.

Future research would benefit from engaging in yet other contexts where other types of issues and services exist, for example sexual surrogate therapy (Shapiro 2017; IPSA 2018), the charity model of sex services (Nakamura 2014; White Hands 2018; Hand Angel 2018), same-gender sexual assistance (NPO Noir 2018), and university-educated and highly professionalized sexual advisors (Handisex 2018; Seksualvejlederforeningen 2018).

But however different the situation is in different societies, there are some commonalities that most disability rights campaigners would recognize, as expressed in the following two quotations:

So if disabled people can't access work and employment, it's also going to impact on how they form relationships, how they're viewed as potential partners of worth and significance, how they're viewed in terms of building families, of keeping a family and so on. So it's linked into all those different areas as well. But the key point is how you take [sexuality] and then embed it within all the different structures (...) which are political, which are economic, which are cultural as well. (interview, European Network for Independent (ENIL) Youth Network)

Sexuality is the result of the whole person's life situation. Without the prerequisites for self-esteem and personal independence there can be no sound sexuality... [F]or many of us who have extensive disabilities our sexual liberation does not so much depend on sex counselling or mechanical sex aids but on the availability of tax-funded personal assistance services which empower us to take control over our own lives. (Ratzka 1998)

In other words, the personal is indeed political, and perhaps even more so when we consider how to achieve sexual citizenship for disabled people in practice. Being able to lead a sexual life of one's choosing is dependent upon the opportunity to live independently in the first place. A sexual rights policy or campaign that is to take disabled people's needs seriously must acknowledge that.

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## References

- Aditi. 2017. *Definition sexual assistance*. Haacht: Aditi. (document provided by interviewee)
- Anderberg, Peter. "ANED country report on the implementation of policies supporting independent living for disabled people." Accessed 24 September 2018. <https://www.disability-europe.net/downloads/593-se-6-request-07-aned-task-5-independent-living-report-sweden-to-publish-to-ec>.
- Askheim, Ole Petter, Hans Bengtsson, and Bjarne Richter Bjelke. 2014. "Personal assistance in a Scandinavian context: similarities, differences and developmental traits." *Scandinavian Journal of Disability Research* 16 (sup1):3-18. doi: 10.1080/15017419.2014.895413.
- Bacchi, Carol, and Susan Goodwin. 2016. *Poststructural Policy Analysis. A Guide to Practice*. New York: Palgrave Macmillan.
- Bahner, Julia. 2015a. "Risky business? Organizing sexual facilitation in Swedish personal assistance services." *Scandinavian Journal of Disability Research* 18 (2):164–75. doi: 10.1080/15017419.2015.1063540.
- . 2015b. "Sexual professionalism: for whom? The case of sexual facilitation in Swedish personal assistance services." *Disability & Society* 30 (5):788–801. doi: 10.1080/09687599.2015.1021761.
- . "Sexual citizenship and disability: implications for theory, practice and policy." <https://scd.leeds.ac.uk> (project website).
- Berkel, Rik. 2013. "From Dutch Disease to Dutch Fitness? Two Decades of Disability Crisis in the Netherlands." In *Disability Benefits, Welfare Reform and Employment Policy*, edited by Colin Lindsay and Donald Houston. Basingstoke: Palgrave Macmillan.
- Blackburn, Maddie, Lizzie Chambers, Sarah Earle, David Raeburn, and Claire De Than. 2016. *Talking about sex, sexuality and relationships: Guidance and Standards. For those working with young people with life-limiting or life-threatening conditions*. Milton Keynes: The Open University. Available online: [http://www.open.ac.uk/health-and-social-care/research/sexuality-alliance/sites/www.open.ac.uk.health-and-social-care.research.sexuality-alliance/files/files/Guidance-40pp\\_03-17\\_email.pdf](http://www.open.ac.uk/health-and-social-care/research/sexuality-alliance/sites/www.open.ac.uk.health-and-social-care.research.sexuality-alliance/files/files/Guidance-40pp_03-17_email.pdf)
- Brennan, Ciara, Rannveig Traustadóttir, Peter Anderberg, and James Rice. 2016. "Are Cutbacks to Personal Assistance Violating Sweden's Obligations under the UN Convention on the Rights of Persons with Disabilities?" *Laws* 5 (2). doi: 10.3390/laws5020023.
- British Institute of Human Rights. "Supporting a disabled man to visit a gay pub." Accessed 26 September 2018. <https://www.bih.org.uk/FAQs/supporting-a-disabled-man-to-visit-a-gay-pub>.
- Carey, Gemma, Eleanor Malbon, Sue Olney, and Daniel Reeders. 2018. "The personalisation agenda: the case of the Australian National Disability Insurance Scheme." *International Review of Sociology* 28 (1):20-34. doi: 10.1080/03906701.2018.1425084.
- Committee on the Rights of Persons with Disabilities. "Concluding observations on the initial report of Sweden." United Nations, Accessed 26 September 2018. [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/SWE/CO/1&Lang=En](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/SWE/CO/1&Lang=En).
- . "Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland." United Nations, Accessed 26 September 2018. [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GBR/CO/1&Lang=En](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GBR/CO/1&Lang=En).
- Commonwealth of Australia. "National Disability Strategy 2010-2020", Accessed 24 September 2018. <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>.
- Contact a Family. "Growing up, sex and relationships." Accessed 20 September 2018. <https://contact.org.uk/advice-and-support/your-child-your-family/growing-up-sex-and-relationships/>.
- DCDD. "Everybody Matters: Stories and practical tips to put an often neglected topic on the map." Accessed 21 September 2018. <http://www.dccd.nl/everybody-matters-stories-practical-tips-put-often-neglected-topic-map/>.
- de Jong, Philip R. 2012. *Recent changes in Dutch disability policy*. The Hague: University of Amsterdam & APE bv. Available online: <https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=2ahUKEwiVkbz>

- [6\\_OLdAhVrLsAKHTTdAIIQFjAAegQICRAC&url=https%3A%2F%2Fwww.ape.nl%2Finclude%2FdownloadFile.asp%3Fid%3D322&usg=AOvVaw2JzJ2rt26fJekGJap9LiUr](https://www.ape.nl/Finclude%2FdownloadFile.asp%3Fid%3D322&usg=AOvVaw2JzJ2rt26fJekGJap9LiUr)
- de Than, Claire. 2015. "Sex, disability and human rights. Current legal and practical problems." In *Supporting disabled people with their sexual lives: a clear guide for health and social care professionals*, edited by Tuppy Owens. London; Philadelphia: Jessica Kingsley Publishers.
- Department of Health. "A Framework for Sexual Health Improvement in England " Department of Health, Accessed 24 September 2018. <https://www.gov.uk/government/publications/a-framework-for-sexual-health-improvement-in-england>.
- Dowse, Leanne, Frohmader, Carolyn & Didi, Aminath. 2016. "Violence Against Disabled Women in the Global South: Working Locally, Acting Globally." In *Disability in the global South. The critical handbook*, edited by Shaun Grech & Karen Soldatic. Cham, Switzerland: Springer.
- EHRC. 2017. *Being disabled in Britain: A journey less equal*: Equality and Human Rights Commission. Available online: <https://www.equalityhumanrights.com/en/publication-download/being-disabled-britain-journey-less-equal>
- Emens, Elizabeth F. 2009. "Intimate discrimination: the state's role in the accidents of sex and love." *Harvard Law Review* 122:1307-14.
- Enhance the UK. "Sex & Disability, The Love Lounge Live." Accessed 27 September 2018. <http://www.enhancetheuk.org/the-love-lounge-live/>.
- EPSEAS. "Vision and goals." Accessed 20 September 2018. <http://www.epseas.eu/en/page/180>.
- . "What is sexual assistance?", Accessed 20 September 2018. <http://www.epseas.eu/en/page/181>.
- Family & Community Services. "Sexuality and Relationship Guidelines." Accessed 28 September 2018. <https://www.facs.nsw.gov.au/download?file=590660>.
- Finger, Anne. 1992. "Forbidden fruit." *New Internationalist* (233). Available online: <https://newint.org/features/1992/07/05/fruit>
- FleksZorg. "Sex care." Accessed 20 September 2018. <http://www.flekszorg.nl/sekszorg.php>.
- FQ. "Statement of aims." Accessed 19 September 2018. <http://www.kvinnor-funktionshinder.se/web/page.aspx?refid=4>.
- . "Hem." Accessed 19 September 2018. <http://www.kvinnor-funktionshinder.se/web/page.aspx?sid=3053>.
- Gagnon, John H., and William Simon. 2005. *Sexual Conduct: The Social Sources of Human Sexuality*. New Jersey: Rutgers.
- Gammino, Giorgia Rosamaria, Elena Faccio, and Sabrina Cipolletta. 2016. "Sexual Assistance in Italy: An Explorative Study on the Opinions of People with Disabilities and Would-Be Assistants." *Sexuality and Disability* 34 (2):157-70. doi: 10.1007/s11195-016-9435-y.
- García-Santesmases Fernández, Andrea, Núria Vergés Bosch, and Elisabet Almeda Samaranch. 2017. "'From alliance to trust': constructing Crip-Queer intimacies." *Journal of Gender Studies* 26 (3):269-81. doi: 10.1080/09589236.2016.1273100.
- Giami, Alain. 2015. "Sexuality, health and human rights: The invention of sexual rights." *Sexologies* 24 (3):e45-e53. doi: 10.1016/j.sexol.2015.07.002.
- Hand Angel. "Home." Accessed 28 September 2018. <http://www.handangel.org/>.
- Handisex. "Home." Accessed 28 September 2018. <http://handisex.dk/?lang=en>.
- Helmius, Gisela. 2004. "Sexualiteten som individuellt och socialt fenomen." In *Genus och funktionshinder*, edited by Karin Barron. Lund: Studentlitteratur.
- IPSA. "Home." Accessed 28 September 2018. <http://www.surrogatetherapy.org>.
- Kool, Jacqueline. 2010. *Eros (un)limited: stories about limbs, life and lust*. Ede: Stichting Kreukelzone.
- Kulick, Don, and Jens Rydström. 2015. *Loneliness and Its Opposite. Sex, Disability, and the Ethics of Engagement*. Durham: Duke University Press.
- Kvale, Steinar, and Svend Brinkmann. 2009. *Den kvalitativa forskningsintervjun [The qualitative research interview]*. Lund: Studentlitteratur.
- Leonard, Cheshire. "Sex and relationships." Accessed 20 September 2018. <https://www.leonardcheshire.org/about-us/latest-news/news-and-blogs/sex-and-relationships>.
- Liddiard, Kirsty. 2014. "'I never felt like she was just doing it for the money': Disabled men's intimate (gendered) realities of purchasing sexual pleasure and intimacy." *Sexualities* 17 (7):837-55. doi: 10.1177/1363460714531272.
- . 2017. *The intimate lives of disabled people*. Abingdon, Oxon; New York, NY: Routledge.
- Lister, Ruth. 2003. *Citizenship: Feminist Perspectives*. New York: Palgrave Macmillan.

- Malmberg, Denise. 2012. "'To be cocky is to challenge norms'. The impact of bodynormativity on bodily and sexual attraction in relation to being a cripple." *Lambda Nordica* (1-2):194-216.
- Nakamura, Karen. 2014. "Barrier-Free Brothels: Sex Volunteers, Prostitutes and People with Disabilities." In *Capturing Contemporary Japan: Differentiation and Uncertainty*, edited by Satsuki Kawano, Glenda S. Roberts and Susan Orpett Long, 202-20. Honolulu: University of Hawai'i Press.
- NDIA. "IAC advice on reasonable and necessary support across the lifespan: An ordinary life for people with disability." Accessed 26 September 2018. <https://www.ndis.gov.au/about-us/governance/IAC/iac-reasonable-necessary-lifespan>.
- . "NDIA response to recent media coverage." Accessed 26 September 2018. <https://www.ndis.gov.au/news/media-response.html>.
- . "Promoting independence for people with disability." Accessed 26 September 2018. <https://www.ndis.gov.au/about-us/governance/IAC/iac-advice-independence.html>.
- NDIS Act. Accessed 27 September 2018. <https://www.legislation.gov.au/Details/C2016C00934>.
- Netherlands Institute for Human Rights. "Rapportage VN-verdrag handicap in Nederland 2017 [Report on the UN Convention of Disability in the Netherlands 2017]." Accessed 25 September 2018. <https://www.mensenrechten.nl/nl/publicatie/38166>.
- New South Wales Government. "Disability Inclusion Act." Accessed 24 September 2018. <https://legislation.nsw.gov.au/~view/act/2014/41/full>.
- NPO Noir. "性的支援について [About sexual support]." Accessed 28 September 2018. [http://www.npo-noir.com/?page\\_id=2159](http://www.npo-noir.com/?page_id=2159).
- Office for Disability Issues. "Fulfilling Potential: improving the lives of disabled people." Accessed 24 September 2018. <https://www.gov.uk/government/collections/fulfilling-potential-working-together-to-improve-the-lives-of-disabled-people>.
- Olsson, Mimmi. 2015. *Fråga, lyssna, var intresserad – en vägledning om sexualitet, känslor och bemötande för dig som arbetar i en LSS-verksamhet [Ask, listen, be interested – a guideline about sexuality, feelings and professional conduct for you working in an LSS unit]*. Sociala resursförvaltningen: Malmö stad. Available online: <https://malmo.se/download/18.70e8cf0b1611e2cb0c9bd/1517479054822/Fr%C3%A5ga%2C+lyssna%2C+var+intresserad+-+En+v%C3%A4gledning+om+sexualitet%2C+k%C3%A4nslor+och+bem%C3%B6tande+f%C3%B6r+dig+som+arbetar+i+en+LSS-verksamhet.pdf>
- Outsiders. "Club, Services." Accessed 27 September 2018. <http://www.outsiders.org.uk/outsidescub/club/services/>.
- . "Helpline." Accessed 27 September 2018. <http://www.outsiders.org.uk/outsidescub/helpline/>.
- . "Home." Accessed 27 September 2018. <http://www.outsiders.org.uk/outsidescub/>.
- Patton, Michael Quinn. 2002. *Qualitative research & evaluation methods*. London: Sage.
- Pring, John. "Scrapped! Ministers 'secretly ditch government's disability strategy'." Accessed 24 September 2018. <https://www.disabilitynewsservice.com/scrapped-ministers-secretly-ditch-governments-disability-strategy/>.
- Ratzka, Adolf. "Sexuality and people with disabilities: What experts often are not aware of." Accessed September 2018. <http://www.independentliving.org/docs5/sexuality.html>.
- Reindl, Marie-Sol. 2014. "If Sex is Care: An exploration of the concept of normalization in the field of disability." Master thesis.
- Reinschmidt, Lena. "Prostitution in Belgium: federal legislation and regulation at the local level." Observatory for Sociopolitical Developments in Europe, Accessed 27 September 2018. <https://www.beobachtungsstelle-gesellschaftspolitik.de/f/18c81917c6.pdf>.
- Richardson, Diane. 2000. "Constructing sexual citizenship: theorizing sexual rights." *Critical Social Policy* 20 (1):105-35. doi: 10.1177/026101830002000105.
- Rijksoverheid. "Betreft Voortgang moties VN-verdrag Handicap [Concerning progress on motions on the CRPD]." Accessed 26 September 2018. <https://www.rijksoverheid.nl/documenten/kamerstukken/2016/12/20/kamerbrief-over-de-voortgang-moties-vn-verdrag-handicap>.
- Rubin, Gayle. 1984. "Thinking sex: Notes for a radical theory of the politics of sexuality." In *Culture, Society and Sexuality: a reader*, edited by Richard Parker and Peter Aggleton, 150-87. London: Routledge.
- Rutgers. "Intimiteit en kwaliteit van leven onlosmakelijk verbonden [Intimacy and quality of life are inextricably linked]." Accessed 27 September 2018.

- <https://www.rutgers.nl/sites/rutgersnl/files/pdf/20150317%20Position%20Paper%20Intimiteit%20en%20kwaliteit%20van%20leven.pdf>.
- . "Who we are, Organisation." Accessed 26 September 2018. <https://www.rutgers.international/who-we-are/organisation>.
- SAR. "Mission." Accessed 20 September. <https://www.stichtingsar.nl/English/missie-uk.html>.
- Schaaf, Marta. 2011. "Negotiating Sexuality in the Convention on the Rights of Persons with Disabilities." *Sur International Journal on Human Rights* 8 (14):113–31.
- Scope. "End the Awkward: sex and disability." Accessed 27 September 2018. <https://www.scope.org.uk/end-the-awkward/sex-disability>.
- . "A to Z of sex and disability." Accessed 27 September 2018. <https://www.scope.org.uk/awkward/a-z>.
- Seksualvejlederforeningen. "In English, Welcome to the Danish Association for Sexuality Advisors." Accessed 28 September 2018. <http://www.seksualvejlederforeningen.dk/in-english/>.
- SHADA. "Home." Accessed 27 September 2018. <http://shada.org.uk/wp2/>.
- Shakespeare, Tom, Kath Gillespie-Sells, and Dominic Davies. 1996. *The Sexual Politics of Disability: Untold Desires*. London: Casell.
- Shapiro, Lawrence. 2017. "The disabled sexual surrogate." *Reproductive Health Matters* 25 (50):134–7. doi: 10.1080/09688080.2017.1333894.
- Shuttleworth, Russell. 2012. "Bridging Theory and Experience. A Critical-Interpretive Ethnography of Sexuality and Disability." In *Sex and Disability*, edited by Robert McRuer and Anna Mollow, 54–68. Durham and London: Duke University Press.
- Sisters, of Frida. "Eleanor Lisney: Disability and Sexuality workshops." Accessed 19 September 2018. <http://www.sisofrida.org/eleanor-lisney-disability-and-sexuality-workshops/>.
- . "Home." Accessed 19 September 2018. <http://www.sisofrida.org>.
- Slater, Jen, and Kirsty Liddiard. 2018. "Why Disability Studies Scholars Must Challenge Transmisogyny and Transphobia." *Canadian Journal of Disability Studies* 7 (2):83-93. doi: <https://doi.org/10.15353/cjds.v7i2.424>.
- Stichting Handicap & Seksualiteit. "Home." Accessed 20 September 2018. <http://www.handicapenseksualiteit.nl/>.
- Svensk, Veronica. 2011. *Hemligheter kända av många – En metod och handbok för dig som har personlig assistans*. Farsta: Förbundet Unga Rörelsehindrade. Available online: <http://enhemlighet.se/wp-content/uploads/2012/03/Hemligheter-kända-av-många.pdf>
- SWAD. "About." Accessed 19 September 2018. <http://www.sexwithadifference.com/page3.php>.
- Tilley, Elizabeth, Walmsley, Jan, Earle, Sarah & Atkinson, Dorothy. 2012. "'The silence is roaring': sterilization, reproductive rights and women with intellectual disabilities". *Disability & Society* 27(3):413-426. doi:10.1080/09687599.2012.654991
- TLC. "Home." Accessed 27 September 2018. <http://tlc-trust.org.uk>.
- Touching Base. "About us, History, Small beginnings." Accessed 20 September 2018. <http://www.touchingbase.org/about-us/history/small-beginnings>.
- . "History, Outcomes of our work." Accessed 20 September 2018. <http://www.touchingbase.org/about-us/history/outcomes-of-our-work>.
- . "Home." Accessed 20 September 2018. <http://www.touchingbase.org>.
- Trailblazers. "It's complicated." Accessed 20 September 2018. [http://www.muscular dystrophyuk.org/wp-content/uploads/2015/04/Trailblazers\\_Relationships\\_Its-Complicated.pdf](http://www.muscular dystrophyuk.org/wp-content/uploads/2015/04/Trailblazers_Relationships_Its-Complicated.pdf).
- UN. 1993. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. Geneva: United Nations. Available online: <https://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html>
- . 2006. *Convention on the Rights of Persons with Disabilities*. Available online: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext>
- . 2017. *Sexual and reproductive health and rights of girls and young women with disabilities. Report of the Special Rapporteur on the rights of persons with disabilities*. Geneva: United Nations. Available online: <https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/Reports.aspx>
- UNFPA. 2018a. *International technical guidance on sexuality education. An evidence-informed approach*. Geneva: UNESCO, UNAIDS, UNFPA, UNICEF, UN Women and WHO. Available online: <https://www.unfpa.org/sites/default/files/pub-pdf/ITGSE.pdf>

- . 2018b. *Young Persons with Disabilities: Global Study on Ending Gender-based Violence and Realizing Sexual and Reproductive Health and Rights*. New York: UNFPA. Available online: [https://www.unfpa.org/sites/default/files/pub-pdf/51936\\_-\\_UNFPA\\_Global\\_Study\\_on\\_Disability\\_-\\_web.pdf](https://www.unfpa.org/sites/default/files/pub-pdf/51936_-_UNFPA_Global_Study_on_Disability_-_web.pdf)
- van der Stege, Heleen A., Sander R. Hilberink, Ellen Bakker, and AnneLoes van Staa. 2016. "Using a Board Game About Sexual Health with Young People with Chronic Conditions in Daily Practice: A Research into Facilitating and Impeding Factors." *Sexuality and Disability* 34 (3):349-61. doi: 10.1007/s11195-016-9448-6.
- Vlaams Parlement. "Conceptnota voor nieuwe regelgeving betreffende het faciliteren van de beleving van seksualiteit en intimiteit op maat van personen met een zorgbehoefte [Concept note for new regulations concerning the facilitation of the perception of sexuality and intimacy tailored to persons with a care need]." Accessed 27 September 2018. <https://www.vlaamsparlement.be/parlementaire-documenten/parlementaire-initiatieven/1208475>.
- WAS. "Declaration of Sexual Rights." [http://www.worldsexology.org/wp-content/uploads/2013/08/declaration\\_of\\_sexual\\_rights\\_sep03\\_2014.pdf](http://www.worldsexology.org/wp-content/uploads/2013/08/declaration_of_sexual_rights_sep03_2014.pdf).
- Weeks, Jeffrey. 2010. *Sexuality*. New York: Routledge.
- Wermeling, Erika. 2017. *FQ 20 år av kamp för jämställdhet och jämlikhet [FQ 20 years of struggle for gender equality]*. Stockholm: Forum – Kvinnor och Funktionshinder.
- White, Hands. "Sexual rights for all." Accessed 28 September 2018. <http://www.whitehands.jp/e.html>.
- WHO. "Defining sexual health." [http://www.who.int/reproductivehealth/topics/sexual\\_health/sh\\_definitions/en/](http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/).
- WHO, and UNFPA. 2009. *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA Guidance notes*. Geneva: WHO. Available online: <https://www.unfpa.org/publications/promoting-sexual-and-reproductive-health-persons-disabilities>
- WWDA. "Background, Aims and Objectives." Accessed 19 September 2018. <http://wwda.org.au/about/background/>.
- WWDA, Youth Network. "About." Accessed 19 September 2018. <http://youth.wwda.org.au/about/>.
- . "Resources, Human rights resources, Position statements." Accessed 19 September 2018. <http://youth.wwda.org.au/resources/human-rights/position-statements/>.
- Yerkes, Mara, and Romke van der Veen. 2011. "Crisis and Welfare State Change in the Netherlands." *Social Policy & Administration* 45 (4):430-44. doi: doi:10.1111/j.1467-9515.2011.00783.x.