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Equal reproduction rights? The right to found a family in United Nations' disability policy since the 1970s

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ABSTRACT

With the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006, disability as an issue of human rights and international law can no longer be ignored. The history of this convention can be traced back to the 1970s, when disability was framed in United Nations (UN) declarations as a human-rights issue at the global level. One of the recurrent topics of debate during this trajectory was the right of people with disabilities to found a family. This right was far from self-evident and was evaluated very differently by various stakeholders.

This study follows the right to have a family in UN disability policy since the 1970s. The history of the family in relation to disability at the global level has been a neglected field of enquiry compared to other concepts such as gender and race. This study investigates how and why the right to found a family was framed in the Declarations on the Rights of Mentally Disabled Persons (1971) and Disabled Persons (1975), the International Year of Disabled Persons (1981), the International Decade of Disabled Persons (1983 – 1992), the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) and the UNCRPD in 2006.

The trajectory of the right of people with disabilities to found a family that emerges from these cases shows a change in the 1990s from a social-policy to a human-rights approach towards disability – which reflects a broader trend in global and local histories of human rights. In the case of reproductive rights of people with disabilities this change meant that the emphasis was laid more on providing a legal protection for the individual against the interference of others (so-called negative freedom) than on enhancing the opportunities for disabled people to practice their (positive) freedom.

KEYWORDS

Disability; family; human rights; reproduction; international law; social policy; utopianism

1. Introduction

A recent landmark for the emancipation of people with disabilities is the adoption of the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006. A lot of disability research since then has been related to the worldwide implementation of this convention. Much less research has been done on the historical trajectory of this convention, whereas history is increasingly studied by international-law scholars (Nijman, 2017). In this paper I will explore the historical trajectory of the right of people with disabilities to found

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a family, as was agreed on in article 23 of the UNCRPD. This article provides that ‘States Parties shall take 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, so as to ensure that: a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized’ (United Nations, 2006).

This ‘right of *all* persons with disabilities’, including people with intellectual disabilities and persons with genetically transferable impairments, ‘to marry and to found a family’ is not self-evident. There is a long and influential (eugenic) tradition of prohibiting the reproduction of people with disabilities, practised, for instance, by sterilizing people with intellectual disabilities (Mitchell & Snyder, 2003). Moreover, the legalization of abortion and the development of prenatal screening in many (Global North) countries have increasingly prevented the birth of people with disabilities in recent decades. The UNCRPD seems not to exclude abortion, since the contested article 25 states that ‘States Parties shall: a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes’ and, as (conservative) critics pointed out, in some countries abortion is included in such programmes (Shaffer, 2009).

Given these developments, it would not only be interesting to see how article 23 is and will be used in specific cases, but – and that is what I want to investigate in this paper – also to ask: what is the history of the right of all persons with disabilities to found a family and how did this right come to be included in UN policies? I will investigate this history on the global level by analysing how and why this right was discussed and formulated during key moments in the history of UN disability policies. As will become clear, the 1990s were a crucial decade in the development of this right. The recent literature about article 23 has shown that the UNCRPD has a more ‘narrow approach to sexuality’ (read: heterosexual approach) than the so-called Standard Rules from 1993 (Ruiz, 2017; Schaaf, 2011). This change can be explained by the influence of conservative actors during the UNCRPD negotiations, but – as I will show – also has to be understood as a shift to a human-rights-based approach in which the emphasis was laid more on negative than on positive freedom.

2. Historiography

Before presenting my analysis of the sources, I want to start by discussing three insights from the human-rights literature that I find useful for understanding the case of disability human rights and article 23 in particular and that will explain my approach to the topic. For more than a decade historians have been devoting more attention to the history of human rights. A key book in the historiographical debates is Samuel Moyn’s *Last Utopia* (2010). In his book Moyn argued that human rights got their current meaning, namely a set of rights grounded in individual dignity that will enjoy secure international protection, only in the 1970s. Before this decade, human rights were understood as collective rights and/or nationally protected rights. Moyn understands human rights since the 1970s as a utopia that became central to a global social

movement. I will not go into the details here, but want to highlight the discussion about human-rights utopianism as the first relevant insight.

Moyn explains the success of the concept and the movement since the 1970s by pointing to the fact that people around that time became disappointed in other political utopias, like anti-colonialism and socialism. Human rights, as brought to the fore by organizations like Amnesty International, became an alternative moral, minimalist utopia. While the focus in *Last Utopia* is on political-human-rights violations, in his recent book *Not enough* (2018) Moyn addresses shortly the recognition of ‘identities beyond those of white males’. Following the feminist trend, according to Moyn, it became ‘impermissible for human rights law and activism to omit women from their ken’ after the Cold War. During the 1990s promoters of women’s human rights focussed on ‘corporal violence as the most burning challenge to face’ (Moyn, 2018, pp. 202–204).

Moyn’s work provoked extensive debate. One alternative understanding of recent human-rights history is in particular relevant for disability rights: Stefan-Ludwig Hoffmann has recently argued that human rights got their current meaning and popularity during the 1990s. Differing slightly from Moyn, Hoffmann stated that ‘in the 1970s and 1980s ‘human rights’ coexisted and overlapped with other moral and political idioms like ‘solidarity’ and included competing notions of rights, which were in many ways still indebted to the legacies of socialism and anti-colonialism, as in, for example, the transnational movement against apartheid’ (Hoffmann, 2016, p. 282). This is in line with what Antony Anghie argued in response to Moyn’s interpretation of the 1970s, pointing to the ongoing relevance of the utopia of development and arguing that ‘human rights was the last utopia for a select group of people, largely based in the West’ (Anghie, 2013, pp. 73–74). Moreover, Hoffmann challenges Moyn’s understanding of human rights as a utopia. He agrees with Moyn that international human rights ‘regained currency first as a critique of revolutionary utopias’, but human rights since the 1990s ‘is everything but future-oriented or utopian. It is not a social or political imaginary of different, more perfect society’. Human rights are ‘a bare human minimum’, states Hoffmann, using Michael Ignatieff’s phrase (Hoffmann, 2016, p. 304). In doing so, Hoffmann interprets human rights in the 1990s as part of a new time regime. He builds on work of historians like François Hartog, who saw 1989 as the end of the modern time regime in which present and past were seen in terms of the future and the beginning of a time regime in which past and future are subordinated to the present. Human rights since the 1990s have been, according to Hoffmann, focussed on the present and used to judge the past with present norms.

As I will show in more detail below, Moyn’s and Hoffmann’s work is helpful in understanding the 1990s as a decade in which the use and meaning of human rights shifted from being part of other utopias to a presentist use of the concept and thus provides a good background for interpreting the history of disability human rights and the right to found a family in particular. In addition, I want to introduce Isaiah Berlin’s distinction between negative and positive freedom or liberty as used by Tom Shakespeare in his work about disability rights as a second relevant insight. Negative freedom concerns the question ‘What is the area within which the subject – a person or group of persons – is or should be left to do or be what he is able to do or be, without interference by other persons?’, while positive freedom is ‘involved in the answer to the question “What, or who, is the source of control or interference that can determine

someone to do, or be, this rather than that?" (Berlin, 1969, p. 118). This distinction is relevant for the reproductive rights of disabled persons, because human rights in their current meaning are often focussed on negative freedom. However, according to Tom Shakespeare, that is only one side of the spectrum: 'restrictions on negative freedom arise when states legislate for who can get married and have children', but, he asks, 'what more can states do positively to enhance the opportunities for disabled people?' (Shakespeare, 2014, p. 214). In the historical investigation of the right to found a family, I will ask whether the focus was on negative and/or positive freedom and how this changed over time.

The third insight from the literature that I want to highlight here is the perspective on global intellectual history as articulated by Samuel Moyn. The literature about the global spread of concepts can often be characterized by what Moyn calls the model of 'truncation and fulfillment'. According to this model, 'once universal entitlements [like human rights] are declared, the pressure rises for remedying their original truncation' and the (metropolitan) elite cannot 'keep these entitlements for themselves, they are forced by the universalism of their own claim to extend them' to '(colonial) subalterns' (Moyn, 2013, pp. 188–189). With the 'immanent "logic"' of this model, argues Moyn, it is difficult to explain why universalisms are not always widely claimed. He therefore states that the co-existence of different concepts, the nonglobalization of ideas and specific interpretation and context of the concept have to be taken into account (Moyn, 2013, pp. 191–197).

3. Analytical approach and sources

Moyn's contextualizing approach has inspired me to not take disability human rights as self-evident and waiting to be fulfilled. On the contrary, I have investigated in the main UN disability-policy documents (see Table 1) as precisely as possible how the concept of (reproduction) rights was used, how this changed over time, how this was related to the use of other concepts, and how we can explain this phenomenon. The sources offer little insight into the precise actors who determined the use of the concepts, which means that an in-depth explanation is not always possible. Nevertheless, this approach enables

Table 1. Analyzed United Nations documents.

Declaration on the Rights of Disabled Persons (1975)
International Year of Disabled Persons (IYDP, 1976), decision of the General Assembly
World Programme of Action concerning Disabled Persons (WPA, 1982), resolution General Assembly and report of the Secretary-General
Report of the Ad Hoc Open-ended Working Group to Elaborate Standard Rules on the Equalization of Opportunities for Disabled Persons: note by the Secretary-General (1992)
Human Rights and Disabled Persons (1993), report of special rapporteur of the sub-commission on prevention of discrimination and protection of minorities
Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993)
Progress report on the preparations for the International Conference on Population and Development (1993)
Human Rights and Disability (2002), report about the current use and future potential of United Nations human rights instruments in the context of disability
Views submitted by Governments, intergovernmental organizations and United Nations bodies concerning a comprehensive and integral international convention on the protection and promotion of the rights and dignity of persons with disabilities: note by the Secretary-General (2003)
United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006)

me to contribute in a new way to the literature about the history of the UNCRPD, that until now has too often focussed on the drafting or on the long-awaited 'fulfillment' (Degener & Begg, 2017; Kanter, 2016; Ruiz, 2017; Schaaf, 2011) and does not always contextualize disability as a contested human-rights issue in broader social and political transformations.

4. Results

4.1. *Human rights before human rights*

An important moment in using the human-rights framework for the case of people with disabilities was the Declaration on the Rights of Mentally Retarded Persons in 1971. People with disabilities were, of course, already implicitly included in the Universal Declaration of Human Rights from 1948, but they received little explicit attention in the additional declarations and conventions with which the UN further elaborated on specific rights or the rights of specific groups – especially since the 1960s. As Gildas Brégain has shown, the right of people with disabilities to found a family received its first serious international discussion during the drafting of the Declaration of General and Special Rights of Mentally Retarded Persons in 1971. During a congress of the International League of Societies for the Mentally Handicapped, the right of people with mental disabilities to vote, to marry and to have children was discussed, but due to strong opposition from parents and professionals these rights were not included (Brégain, 2018, pp. 164–166). Four years later the Declaration on the Rights of Disabled Persons (1975) was adopted by the General Assembly. This short declaration stated that disabled persons had 'the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible'. The declaration did not explicitly deal with reproductive rights, and the family was mentioned only as follows 'Disabled persons have the right to live with their families or with foster parents' (United Nations, 1975).

How these declarations were applied at the global level becomes clear from the UN's observance of the International Year of Disabled Persons (IYDP) in 1981 and the International Decade of Disabled Persons (1983–1992), two initiatives to call attention to the situation of people with disabilities worldwide and to stimulate improvement of the often disadvantaged position of people with disabilities, especially in the so-called developing countries. Since 1959 the UN has been dedicating years, days and decades to particular topics to influence the global agenda, and following a proposal by Libya, the General Assembly chose 1981 as the IYDP (United Nations, 1976). The central theme of the year was identified as 'full participation and equality' and announced with the following formulation: "full participation' of disabled persons in the social life and development of societies in which they live, 'equality', meaning living conditions equal to those of other citizens in their society, and an equal share in the improvement of living conditions resulting from social and economic development' (United Nations, 1982b, p. 19). National governments and international organizations were asked to initiate activities that supported the main objectives linked to this theme: giving disabled people what they need for their full participation in society, investing in the prevention of disability and 'educating and informing the public of the rights of disabled

persons to participate in and contribute to various aspects of economic, social and political life' (United Nations, 1976). As in the case of the declaration, the right to found a family was implicitly included, but did not receive explicit attention. At the same time, prevention of disabilities was one of the priorities of the year, although this seemed not to include prenatal prevention.

During the IYDP, as was often the case during international years, a World Programme of Action was drafted (United Nations, 1982a). The so-called World Programme of Action concerning Disabled Persons (WPA) had almost the same aim as the international year: 'living conditions [of people with disabilities] equal to those of other citizens in their society'. The relevant terms of action proposed in the Programme were defined as prevention, rehabilitation and equalization of opportunities. Parallel to the making of the WPA, the UN decided to launch a Decade of Disabled Persons for the years 1983–1992 that 'could serve as a time-frame for the implementation of the World Programme of Action' (United Nations, 1982b, p. 8). In the WPA documents there were references to human rights, but human rights, let alone the right to found a family, certainly were not a central notion of the programme. Prevention, on the other hand, was one of the priorities. The declaration of 1975 was thus initially not interpreted as a stimulant to further elaborate on the human rights of or international law concerning people with disabilities, but as a document that underlay social policies aimed at improving the societal participation and living conditions of people with disabilities. This is no surprise, since the main responsibility for UN disability policies was assigned to the Economic and Social Council of the UN and not to the Commission on Human Rights. Moreover, the way in which the declaration of 1975 was used reflects what Hoffmann states about human rights in the 1970s and 1980s: they were part of other visions of the future and not a utopia in themselves.

Nonetheless, during the 1980s we can also observe increasing interest in an international-human-rights and international-law perspective on disability – although the right to found a family received no special attention. In 1984 the Commission on Human Rights recommended a 'thorough study of the causal connection between serious violations of human rights and fundamental freedoms and disability as well as of the progress made to alleviate problems' (Despouy, 1993). It took a while before this study was undertaken (see below) but it shows the dawning of a new perspective. This became even more clear when during an expert meeting about the implementation of the WPA in 1987 in Stockholm, the idea of a convention emerged. It was recommended that 'the General Assembly convenes a special conference on the rights of persons with disabilities, with the mandate to elucidate such rights and to draft an international convention on the elimination of all forms of discrimination against disabled persons, to be ratified by States by the end of the Decade, in 1992' (United Nations, 2003). The governments of Italy and Sweden submitted proposals to the General Assembly in this direction but to no avail. Ultimately, at the end of the Decade, in 1993, an agreement was reached on a non-binding instrument, the Standard Rules on Equalization of Opportunities for Persons with Disabilities, 'promoting disability-sensitive policy design and evaluation, as well as technical cooperation' (United Nations, 2003). As will become clear in the next section, we can see in hindsight the beginnings of a rights-based approach in the Standard Rules, although the social-policy approach followed during the International Year and Decade was still prominent in the beginning of the 1990s.

4.2. From planning policy to claiming rights

With the declaration of 1975 the reproductive rights of people with disabilities more or less disappeared from official UN policies concerning people with disabilities, but in the Standard Rules they were again addressed. Rule 9 was about 'family life and personal integrity' and stated that national states have to 'ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood'. Moreover, 'persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood' and 'states should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities, especially of girls and women with disabilities, which still prevail in society' (United Nations, 1993a, p. 18). The right to found a family has never been so strongly addressed in UN disability policy (Schaaf, 2011). In Rule 9 of the Standard Rules we can observe a mix of what Berlin has coined as positive and negative freedom: The promotion of 'measures to change negative attitudes' could be read as a more positive incentive, but in general in Rule 9 the emphasis was on eliminating the interference of others.

The attention to sexuality in the Standard Rules seems to be part of a global trend. It was probably AIDS and the increasing awareness of the importance of the provision of information about sex during the 1980s and 1990s that stimulated the concern about the sexuality of people with disabilities. This concern was further accelerated by the de-institutionalization of people with disabilities: people with disabilities were often for the first time seen as independent citizens who could develop their own (sexual) relationships without institutional mediation. Therefore during the 1990s sexuality was addressed in the academic discipline of disability studies more extensively than before (Schaaf, 2011, p. 114). In disability activism and studies, as developed during the 1970s and 1980s, priority was given to other issues, but in the 1990s – according to Tom Shakespeare – sexuality rights became recognized as central in the struggle for emancipation (Schaaf, 2011). Of course, the attention to sexuality was not entirely new: in one of the founding texts of the American disability movement, the book *Missing Pieces. A Chronicle of Living With a Disability* (1982), sociologist and activist Irving Kenneth Zola had addressed the topic. In his analysis of *Het Dorp*, a Dutch neighbourhood designed and built for people with physical disabilities in the 1960s, he observed how sexuality was denied: 'sexual counselling was not a part of the services for residents nor were any housing provisions made for married couples' (Zola, 1982, p. 215).

It is also no accident that Rule 9 about the family showed a rights-based approach. In 1993 a statement comparable to this rule was made during a Conference on Population Development, where participants brought forward arguments for the 'recognition of the needs of disabled persons concerning, inter alia, sexual and reproductive health, including family-planning services and elimination of the specific forms of discrimination that disabled people may face with regard to international migration, reproductive rights and household and family formation' (United Nations, 1993b, p. 17). The attention in both population and disability policies on restrictions of negative freedom was relatively new, but reflects a broader tendency to protect the individual from the interference of others. According to Marta Schaaf, a paradigm shift took place in the 1990s: 'reproductive autonomy was recast as an objective, in contrast to earlier population control or pro-

natalist orientations' (Schaaf, 2011, p. 118; cf. Hoffmann, 2016, p. 302). As Matthew Connelly has shown in his book *Fatal Misconception* (2010), this shift has its roots in the 1970s, when the aim to plan other people's families was increasingly replaced by the recognition of the rights of reproduction for individuals and in particular women.

The increasing attention to human rights also seemed to be part of a broader interest to view the situation of 'vulnerable groups' through the lens of human rights and international law. In the case of women's rights for instance, the 1990s show not only the rise of the ideal of reproductive autonomy, but also increasing attention to the vulnerability of women, especially to become victims of corporal violence. Women, as Zain Lakhani states, 'have been written, essentially, into international law predominantly through their experience of harm' (quoted by Hoffmann, 2016, p. 302). People with disabilities were also approached in this way, as becomes clear from the 1993 report *Human Rights and Disabled Persons* of the Argentine human-rights lawyer Leandro Despouy, commissioned by the Human Rights Commission in 1984, in which it was stated that 'persons with disabilities are going to find themselves at a legal disadvantage in relation to other vulnerable groups such as refugees, women, migrant workers (...) unlike the other vulnerable groups, they do not have an international control body to provide them with particular and specific protection' (Despouy, 1993).

Despouy's suggestions were, however, only partly followed up in the Standard Rules. As Gerard Quinn and Theresia Degener have observed, the 'traditional preoccupations of prevention and rehabilitation have been relegated [in the Standard Rules] to the background in favour of the rights perspective' (Quinn & Degener, 2002, p. 35). We should, however, not exaggerate, as the intention of the Rules was not to develop new international law. After the failed attempts of Italy and Sweden in the late 1980s, the realization of a convention seemed not feasible in the short term. The Rules stated that 'the purpose of the Rules is to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others', but also that 'existing human rights documents seemed to guarantee persons with disabilities the same rights as other persons' (United Nations, 1993a, p. 5). During the negotiations the representative of the United States had explicitly stated that the 'draft Rules should also be amended to eliminate the suggestion that they were likely to become customary international law (United Nations, 1992, p. 6). Although some countries and activists continued to strive for a convention, the UN mainly aimed at improving the societal participation and living conditions of people with disabilities by planning social policy and not by making international law.

As Rule 9 showed, however, the human-rights approach was seen as relevant for family life and personal integrity. In his report Despouy had already noted that the family rights of disabled persons were violated in some countries by preventing people with disabilities from marrying for eugenic reasons, sometimes with compulsory sterilization practices. Such human-rights violations attracted more attention during the 1990s, as became clear from the pivotal study of the disability-human-rights experts Quinn and Degener, titled *Human rights and disability* (2002). They noted that 'Many restrictions are still placed on family and privacy rights for people with disabilities, especially those in institutions, throughout the world. Their right to adopt children on an equal footing with others is a virtually unrecognized issue on which little has been written' (Quinn & Degener, 2002, p. 24). To some extent, existing international law

provided protection, 'but a clear statement that disability per se should never be regarded as a legitimate ground for sterilization and restrictions on marriage would have been even more helpful' (Quinn & Degener, 2002, p. 75). With this and other arguments, the authors made a plea for a specific disability convention, which became a reality a couple of years after their investigation.

4.3. Negotiating the convention

The fact that Mexico was successful in proposing the drafting of an international convention to the General Assembly in 2001 can partly be explained by the framing 'in light of the Millennium Development Goals': disabled people were not identified as a target group for action and 'only a disability-specific convention would ensure that people with disabilities would not be left behind in the fight against global poverty' (Heyer, 2015, p. 172–173). When we compare Mexico's success with the failed attempts in the late 1980s, we also have to search for an explanation in the 1990s: what changed in this decade? In addition to the trends mentioned in the previous section, I would say that three developments contributed to making the UN soil more fertile for a convention than it had been in the late 1980s. In the first place, the disability movement at the local and global levels increasingly framed its struggle for emancipation in terms of human rights and different groups worked together more than before (Degener & Begg, 2017; Herzog, 2018; van Trigt, 2015). Secondly, several countries included disability in their antidiscrimination law and came to see disability as an equal-rights issue (Kanter, 2016). In the third place, the Standard Rules and their monitoring produced data about the situation of disabled persons worldwide and a stronger institutionalization of the disability movement at the UN level (Degener & Begg, 2017).

With the adoption of the UNCRPD in 2006 human rights became the leading principle for the UN's disability policy. Compared to other international-human-rights law, the convention explicitly deals with the way in which rights have to be implemented and guaranteed, including setting out the duties of member states to people with disabilities. Moreover, the convention is relatively sensitive to 'issues of structural power and oppression' (Mégret, 2008). If we focus on article 23, we can observe that it is in line with Rule 9 – with the difference that the UNCRPD articles are binding and the Standard Rules were not. However, as Schaaf has pointed out, the draft text for the convention article was closer to Rule 9. The proposed text read: 'states should promote the full participation of persons with disabilities in family life. They should promote their rights to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood', 'persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood' and 'states should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities, especially of girls and women with disabilities, which still prevail in society'. Because of opposition of the Roman Catholic Church and a couple of countries and NGOs during the negotiations, sexuality was deleted because this word with 'numerous cultural concerns' did not appear in any other convention. Moreover, the article text had – according to this coalition – to avoid any mention of sexual relationships and parenthood out of the context of marriage because that 'would

mean that the CRPD went into “uncharted and controversial directions” (Schaaf, 2011, pp. 121–123; cf. Ruiz, 2017).

With the UNCRPD the right of people with disabilities to found a family became internationally protected, but the negotiations show that this right is less self-evident for non-heterosexual and unmarried people – especially compared to the non-binding Standard Rules of 1993. Moreover, as Felime Jaramillo Ruiz has argued on the base of analysing the so-called concluding observations of the Committee on the Rights of Persons with Disabilities, the committee ‘has sustained a protective, medical, and gender binary model to address the sexual and reproductive rights of persons with disabilities’ (Ruiz, 2017, p. 92). These critical evaluations about the right to found a family in the UNCRPD often focus on the conservative influence in the drafting process. Equally important and not reducible to conservative actors like the Catholic Church and its allies at the global level is the difference between the UNCRPD, on the one hand, and the draft text and Standard Rules, on the other, regarding negative and positive freedom. The UNCRPD focuses on restrictions on negative freedom, but with the use of the term ‘promote’ the other texts challenged states to contribute in a positive way to the reproductive and sexual rights of people with disabilities. Again we can observe what Hoffmann has written about human rights since the 1990s, namely that the concept is increasingly used in a presentist way as a ‘bare minimum’ and not as (part of) a utopia. With the UNCRPD individuals with disabilities could protest against the interference of others (claiming their ‘bare minimum’), but the convention hardly foresees societal structures that guarantee a more inclusive society.

5. Conclusion

The exploratory history of the right of people with disabilities to found a family, as part of the UNCRPD, shows how there were attempts to include this right in the Declaration on the Rights of Mentally Retarded Persons in the early 1970s. This attempt was blocked: during the 1970s and 1980s, the UN gave priority to advancing the participation of people with disabilities in their respective societies, without focussing on reproductive rights. Human rights did underlie this policy, but international-human-rights law was not something the UN aimed at. This changed in the 1990s, when disability was increasingly approached from a (human) rights perspective. The UN’s disability policy did reflect a broader trend here: where human rights until the 1990s were often part of larger utopian visions, during the 1990s the concept came to the fore in different policy areas and was often more oriented to the present and the past than the future. In the case of the right to found a family, this means that in the beginning of the 1990s we can observe in the UN Standard Rules (1993) a serious attempt to approach reproductive rights in a positive way and to challenge societies to change their attitudes. However, with the emergence of a new paradigm of human rights in the 1990s the emphasis was laid more and more on eliminating the interference of others. During the negotiations of the UNCRPD it was also easier to agree on negative freedom. Given the violence directed at people with disabilities, it is a great gain that their reproductive rights are now part of international law. At the same time, we can ask whether the UNCRPD affords enough to ensure that people with disabilities not only have the right, but also the

opportunity and means to found a family. Does the UNCRPD really provide tools to challenge societal attitudes and structures? From the historical trajectories as presented in this paper we can ask whether we do not need a more future-oriented utopia to change the present.

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