Inequality in Global Disability Policies since the 1970s

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Introduction

The current attention to the history of global economic inequality is fostering additional interest in exploring other types of inequalities and the relationships among them.[1][2] This interest is, according to some scholars, preceded by several decades of neglecting economic inequality in favour of addressing other issues, often under the banner of identity politics. Nancy Fraser, for instance, argued shortly after Donald Trump's election as U.S. President against progressive neoliberalism, defined by her as "an alliance of mainstream currents of new social movements (feminism, anti-racism, multiculturalism, and LGBTQ rights) on the one side, and high-end "symbolic" and service-based business sectors (Wall Street, Silicon Valley, and Hollywood), on the other." Progressive neoliberalism is, according to her definition, against the discrimination of groups like the LGBTQ community, but maintains or even stimulates economic inequality.[3] Fraser's argument echoes a debate with German

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[2] Kenneth McGill, *Global Inequality* (Toronto: University of Toronto Press, 2016); Pedro Ramos Pinto, „The Inequality Debate: Why Now, Why like This?", *Items. Insights from the Social Sciences* (2016), https://items.ssrc.org/the-inequality-debate-why-now-why-like-this; Göran Therborn, „Dynamics of Inequality", *New Left Review* 103 (January-February 2017), https://newleftreview.org/II/103/goran-therborn-dynamics-of-inequality.

[3] Nancy Fraser, „From Progressive Neoliberalism to Trump—and Beyond", *American Affairs* I, 4 (Winter 2017): 46–64, https://americanaffairsjournal.org/2017/11/progressive-neoliberalism-trump-beyond/. Cf. Jessica Whyte, "Powerless companions or fellow travellers? Human rights and the neoliberal assault on post-colonial economic justice", *Radical Philosophy* 2.02 (2018) 13-29.

scholar Axel Honneth more than a decade ago, which addressed the recognition of societal groups. One of Fraser's main arguments in that debate was that recognition and related identity politics are not in themselves sufficient for an inclusive society. We must also strive for a more equitable distribution and redistribution of resources and, thus, greater economic equality.[4] Recent historical work appear to confirm her assessment: Samuel Moyn, for example, combined his thesis on the rise of human rights since the 1970s with the neglect of redistribution and economic inequality at the global level during the same period. Status equality, which, according to Moyn, means that "no one ought to be treated differently because of the kind of person they are," is currently more accepted than ever, but consensus on material equality has been much harder to achieve.[5]

Against the backdrop of these debates on inequality and on which type of inequality is the most urgent to address, I will focus in this chapter on the particular case of global disability policies from the 1970s and onwards. Societies have often viewed people with disabilities as unequal to their able-bodied counterparts, and this situation provoked diverse attempts to conceptualize and fight this inequality. Since the 1970s, people with disabilities have increasingly taken the lead in these attempts. Moreover, these attempts acquired a more 'global' framework: both the grassroots movements of people with disabilities and related policies became internationalized. In addition, these debates directly forged links between observations on the inequality of people with disabilities in concrete, local or national settings and analyses of inequality as a fundamental condition occurring all over the world. In the

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[4] Nancy Fraser and Axel Honneth, *Redistribution or recognition? A political-philosophical exchange* (London/ New York: Verso, 2003).

[5] Samuel Moyn, *Not Enough. Human Rights in an Unequal World* (Cambridge, MA/ London: The Belknap Press of Harvard University Press, 2018), 3.

literature, discussed below, the recent history of conceptualizing the inequality of people with disabilities is often presented as moving from a welfare state approach to disability to more of a human rights and anti-discrimination one. This shift would imply turning from a focus on socio-economic equality to status equality. In her book about disability rights, Katharina Heyer stated that considering disability as a human rights issue, particularly since the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD from 2006), was "unthinkable just twenty years earlier when most countries relied on charity, social welfare, segregated institutions, and sometimes employment quotas to incorporate people with disabilities or mitigate the suffering brought about by their exclusion." The 1990 Americans with Disabilities Act is generally seen as the "world's first comprehensive disability anti-discrimination law," and therefore, as the "first political expression" of a new approach to disability.[6]

However, this chapter shows that the shift in global disability policies is far more complicated than suggested in the research literature, where an Anglo-American perspective has reigned. If one also considers disability activism outside the Anglo-American context, it becomes difficult to maintain the view that the global disability movement has made this shift. Recent debates about the UN Convention on the Rights of Persons with Disabilities have increasingly revolved around the question of how to translate human rights to "the circumstances of people experiencing extreme poverty, displacement and living in repressing regimes."[7] Moreover, the struggle for socio-economic equality was often more important in

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[6] Katharina Heyer, *Rights Enabled. The Disability Revolution, From the US, to Germany and Japan, to the United Nations* (Ann Arbor: University of Michigan Press, 2015), 2.

[7] Monika Baár, „De-pathologizing Disability: Politics, Culture and Identity", *Neue Politische Literatur* 62 (2017): 281-303: 298.

Anglo-American countries than otherwise suggested. I will present the history of UN disability policies as revolving to a much lesser degree around status equality and human rights than the literature suggests. Since disability can be linked to different forms of equality and inequality, varying from poverty to discrimination, it is worthwhile looking at what has actually occurred at the UN since the 1970s. I will focus mainly on how a selection of official UN documents and processes addressed inequality. My main ambition is to examine the extent to which the thesis about this presumed shift in focus from socio-economic (in)equality to human rights and status equality can be verified on the basis of a detailed analysis of these documents.

Inequality and the Global Disability Movement

The dominant historical narrative about the struggle for equal rights among people with disabilities connects different parts of Anglo-American disability history with what has occurred at the UN level. Before I problematize this narrative, I will briefly present what this narrative entails. A major shift that one encounters in almost every text on disability in the last few decades is the shift from the so-called medical model of disability to the social model. According to the medical model, disability is an individual deficit, while the social model perceives disability as a social construct. The shift is often attributed to the Anglo-American context from the 1970s and 1980s because at that time, people with different disabilities found each other in their struggle for emancipation. Before that time, cross-disability activism aimed at equal citizenship hardly existed. People with disabilities were organized on the basis of disability type – blindness, for example – and activism focused mainly on improving social services. Society understood people with disabilities (as they also

understood themselves) as being in a paradigm of social welfare in which medical experts played an important role in determining disability. Robert Drake summarized this point clearly: "welfare is still significantly about changing the individual to fit into the social and physical environment rather than altering the social, political, and physical contours of society."[8]

The shift, which the social model of disability brought about, was that people with disabilities increasingly united themselves in cross-disability groups that were combatting discrimination in ways similar to those of the social movements of women, ethnic minorities and LGBTQ people. The Americans with Disabilities Act (1990) is therefore seen as a landmark event in the emancipation of people with disabilities. The shift towards the social model and a new focus on anti-discrimination are often presented as entangled with a shift towards a human rights approach to disability. As Jane Campbell and Mike Oliver put it: "disabled people began to recognize that the problem of disability is externally located and that our exclusion from society is a human rights issue."[9]

The entanglement of the shift from the medical to social model with the shift away from welfare to human rights can certainly be observed in the history of influential disability groups in the UK and the US. In addition, this shift has often functioned as an inspiring example for activist groups in other countries. However, from a historical perspective it is questionable if this shift can serve as a major explanatory factor in understanding the new

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[8] R.F. Drake, "Welfare States and Disabled People", in *Handbook of Disability Studies*, ed. Gary L. Albrecht, Katherine D. Seelman, Michael Bury (Thousand Oaks/ London/ New Delphi: Sage Publications, 2001), 412-430: 416.

[9] Jane Campbell and Mike Oliver, *Disability politics: understanding our past, changing our future* (London: Routledge, 1996) 62. See for differences between the US and the UK: Heyer, *Rights Enabled*, 47-50.

dynamisms of the disability movements worldwide, let alone the history of UN disability policies. Often, different strands of disability history are tied together to create a smooth narrative with a clear teleology and the worldwide implementation of the UN Convention on the Rights of Persons with Disabilities as a 'logical' outcome. Even the more nuanced contributions tend to underline the centrality of the Anglo-American approach to disability as an issue of discrimination.[10]

 The first important point to make is that this narrative overlooks disability histories from other parts of the world. Moreover, not only does it ignore alternative approaches to disability, but its treatment of Anglo-American history is also rather monolithic and devoid of nuances. Gildas Brégain wrote about disability protests in Argentina, Brazil and Spain during the period of 1968-1982 and relativized "the originary and original manner of the Anglo-American protests within the growth of disability rights movement at the international level."[11] Monika Baár has argued that:

> contrary to other (capitalist) countries where the efforts of self-determination were directed against the patronising attitudes of medical and professional experts, disabled activists in Hungary were actively and wholeheartedly assisted in their emancipatory desires by these professional groups.[12]

[10] Heyer, *Rights Enabled*.

[11] Gildas Bregain, "An entangled perspective on disability history: The disability protests in Argentina, Brazil and Spain", in *The Imperfect Historian. Disability Histories in Europe*, ed. Sebastian Barsch, Anne Klein and Pieter Verstraete (Frankfurt am Main: Peter Lang, 2013), 133-153: 153.

[12] Monika Baar, "Informal Networks, International Developments and the Founding of the First Interest-Representing Associations of Disabled People in Hungary in the Late Socialist Period (1970s-1980s)", *Moving the Social* 53 (2015), 39-62: 39.

Landmine survivors in late twentieth-century Northern Uganda, as Herbert Muyinda has shown, did not take a human rights approach, but pursued the contested approach of "special needs."[13] A closer look to the UK reveals that, as Gareth Millward's work among others suggests, not only did disability activism begin by addressing welfare issues such as poverty, but social security also remained an important issue despite the rise of the social model.[14]

These examples of scholarship could be extended, but what they immediately indicate is that the 'shift-narrative' does not cover different approaches to disability as determined by specific contexts. That does not challenge the fact that parallels and transnational exchanges between countries exist; however, disability histories as mentioned above do not support the idea that one cohesive global movement changed the understanding of disability from a medical/ welfare model to a social/ human rights model in the 1970s. I will support this argument by analysing the UN disability policy and in particular the United Nations' International Year of Disabled Persons (IYDP, 1981), with the theme 'full participation and equality', and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (SREOPD, 1993). This analysis will be carried out in order to address the following two questions: 1) which form of inequality was seen as the most urgent to address? and 2) was there a shift in focus over time from socio-economic (in)equality to human rights?

The International Year of Disabled Persons (1981)

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[13] Herbert Muyinda, "Negotiating Disability: Mobilization and Organization among Landmine Survivors in Late Twentieth-Century Northern Uganda", in *Disability Histories*, ed. Susan Burch and Michael Rembis (Urbana/Chicago/ Springfield: University of Illinois Press, 2014) 98-115: 112-113.

[14] Gareth Millward, "Social Security Policy and the Early Disability Movement—Expertise, Disability, and the Government, 1965–77", *Twentieth Century British History* 26, 2 (2015), 274-297.

The 'official' UN narrative on disability policies echoes almost exactly the shift that has become dominant in the understanding of the Anglo-American disability movement, namely, from welfare to anti-discrimination and human rights since the 1970s.[15] UN disability policies before the 1970s have not yet been studied in great detail, but existing literature clearly shows two things; 1) that disability was hardly explicitly mentioned in the fundamental human rights documents and 2) that the UN were involved in (development) programmes focusing on disability prevention and rehabilitation.[16] Although rehabilitation can be understood as a means to render people with disabilities equal to other citizens in their functioning, the concept of equality or equal rights did not appear to be the central concept in international disability policies during the first decades after the Second World War.[17]

Since the 1970s, disability has increasingly received attention from the UN and its specialized agencies. In 1975, the concerns of people with disabilities received recognition by the General Assembly with the United Nations Declaration on the Rights of Disabled People. On the one hand, this declaration emphasized their equality, but on the other, the underlying approach to disability with which this declaration operated was the medical model.[18] It

[15] Division for Social Policy and Development, *The United Nations and Disability. 70 years of the work towards a more inclusive world* (New York and Geneva: United Nations, 2018), https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2018/01/History_Disability-in-the-UN_jan23.18-Clean.pdf.

[16] Gildas Brégain, *Pour une histoire du handicap au XXe siècle. Approches transnationales (Europe et Amériques) [Towards a history of disability in the twentieth century. Transnational approaches (Europe and the Americas)]* (Rennes: Presses Universitaires de Rennes, 2018).

[17] Gildas Brégain, „The role of international institutions in the process of categorization of 'disabled people' (1930s-1975)", in *The Routledge History of Disability,* ed. Roy Hanes, Ivan Brown and Nancy E. Hansen (London/ New York: Routledge, 2018), 117-132.

[18] Division Social Policy, *United Nations and Disability*. See for the development of the declaration: Brégain, *Pour une histoire* and a chapter of Anaïs van Ertvelde in the forthcoming volume *Marginalized Groups, Inequalities and the Post-War Welfare State: Whose Welfare?*

focused on the social services that would ensure their right "to enjoy a decent life, as normal and full as possible."[19] The declaration framed disability as primarily welfare issues rather than a human rights issue. The same trend is also observable in the International Year of Disabled Persons in 1981.

Since the 1960s, the United Nations have observed international days, weeks, years and decades which have been dedicated to a variety of causes: refugees, women, anti-apartheid. After the year of women (1975) and the year of the child (1979), the UN General Assembly declared, based on a proposal from Libya in 1976, the year 1981 as the International Year of Disabled Persons. As the following formulation reveals, its central theme became "full participation and equality:" "'full participation' of disabled persons in the social life and development of societies in which they live; and '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." The Centre for Social Development and Humanitarian Affairs, part of the Economic and Social Council of the UN, undertook the responsibility for the organization of the year. Concerned national governments and organizations were asked to initiate activities that would support the main objectives linked to this theme: giving disabled people what they need for their full participation in society, investing in rehabilitation and the prevention of disabilities, 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'.[20]

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[19] Article 3 of the United Nations Declaration on the Rights of Disabled Persons (1975), see: https://www.ohchr.org/EN/ProfessionalInterest/Pages/RightsOfDisabledPersons.aspx.

[20] United Nations, World Programme of Action concerning Disabled Persons [A/37/351/Add.1], 1982, https://documents-dds-ny.un.org/doc/UNDOC/GEN/N82/238/48/pdf/N8223848.pdf?OpenElement.

The theme of the International Year reflected the shift in the self-understanding of Anglo-American disability groups from a focus on welfare and rehabilitation to participation and equality. Initial preparations for the year became contested, and because of vigorous protests the concept of equality was integrated into the documents. Moreover, tellingly, 'year for' in the title was replaced with 'year of'.[21] The significance of this seemingly minor change should not be underestimated: people with disabilities should no longer be a passive object of UN policies. During the year, disability activists in different countries organized their own activities and protested against the official celebrations because precisely the issues they found to be important were insufficiently taken into account by politicians and policy-makers.[22] The year 1981 also observed a 'revolutionary' development: disabled representatives from across the globe founded the first international cross-disability organization during a meeting in Singapore: Disabled Peoples' International (DPI). The aim of this brand new organization was "to become the voice of disabled people," and it asserted "that disabled people should be integrated into society and participate with the same rights as everyone else."[23] However, this countermovement was only partly effective at the UN level. Although the UN Centre for Social Development and Humanitarian Affairs used the words 'participation' and 'equality', the emphasis continued to remain on prevention and on the ways disabled people could be supported in their participation in society, including rehabilitation. The question as to how society (and law) could be changed (structurally) in

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[21] See for first version: United Nations, International Year of Disabled Persons [General Assembly], 1976, http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/31/123.

[22] Monika Baar, "The European 'Disability Revolts' of 1981: How Were They Related to the Youth Movement?", in *A European Youth Revolt: European Perspectives on Youth Protest and Social Movements in the 1980s,* ed. Knud Andersen and Bart van der Steen (Houndmills: Palgrave MacMillan, 2016), 159-171.

[23] D. Driedger, *The Last Civil Rights Movement. Disabled People's International* (London: Hurst, 1989), 1.

such a way that disabled people became equal citizens remained largely absent from the UN agenda. The International Year of Disabled Persons thus stimulated, as an unintended consequence, disability activism and alternative approaches to disability, but this did not immediately result in a shift at the global level or in the perception of international organizations.

<<figure 8.1. about here>>

Professor Theresia Degener (foreground left), Chair of the Committee on the Rights of Persons with Disabilities, addresses a roundtable on inclusion and full participation of persons with disabilities in humanitarian action on 14 June 2017. As an activist, Degener was part of the so-called cripple tribunal for human rights violations against people with disabilities in West-Germany during the International Year of Disabled Persons (1981). She became a leading expert in disability rights and law who was for instance involved in the drafting of the Convention on the Rights of Persons with Disabilities (2006). Degener was born without arms due to Contergan, a sleeping drug with unforseen effects (UN Photo/Kim Haughton, available on Flickr.com)

Link to picture: https://www.flickr.com/photos/un_photo/35615802705

This becomes clear when looking at how the case of people with disabilities was addressed in the so-called World Program of Action Concerning Disabled Persons (WPA), developed during the year and later linked to the proclamation that declared the period from 1983 to 1992 as the United Nations Decade of Disabled Persons. The WPA was described by the

member of Disabled Peoples' International Henry Enns from Canada as 'a declaration of emancipation'. According to him, Disabled Peoples' International was "largely successful in having its views incorporated into the WPA," particularly in recognition of people with disabilities as "citizens with rights" and viewing organizations of people with disabilities as "the voice of disabled people." Enns argued that the first draft from 1980 was still medical-model oriented, but the final version from 1982 affirmed that "disabled people are first and foremost citizens with rights, and second, clients of social services (paragraph 25)."[24] In the documents of the Dutch committee that was responsible for the national observances of the International Year in 1981 as well as the international negotiations, it was mentioned that the draft version of the World Programme of Action was criticized by countries such as Canada and Sweden because it excessively followed the 'traditional line of helping the disabled' instead of 'creating conditions which ensure that people with disabilities integrate in society'. Canada ensured that the following paragraph on human rights was added to the plan:

> Full participation in the basic units of society – family, social groups and community – is the essence of human experience. The right to equality of opportunity for such participation is set forth in the Universal Declaration of Human Rights and should apply to all people, including those with disabilities. In reality, however, disabled people are often denied the opportunities of full participation in the activities of the socio-cultural system of which they are a part. This deprivation comes about through physical and social barriers that have evolved from ignorance, indifference and fear.[25]

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[24] Driedger, *Last Civil Rights*, 97.

[25] Nationaal Archief Den Haag, Commissie Internationaal Jaar Gehandicapten (toegang 2.27.07), inventaris 6, attachment to meeting 17 september 1981 (Dutch quotes translated by author).

In all likelihood, the integration of such sentences was not self-evident but was fought for vigorously. Such amendments opened a new societal perspective on disability. However, the question arises as to whether they also justify the framing of the WPA as 'a declaration of emancipation' and a shift towards a new approach.

A closer look at the WPA shows that the general tendency was the same as the broader aim of the International Year: 'living conditions equal to those of other citizens in their society'. The relevant terms of action proposed in the World Programme of Action were defined as prevention, rehabilitation and equalization of opportunities. It becomes evident from the documents that disability was first and foremost considered a development issue, something that often seems to be overlooked in the literature. Already during the year, national committees in the Global North, as in the Dutch and Scandinavian cases[26], decided to spend money and time on the 'Third World'. The prevailing thought was that the more developed countries already secured 'various social rights of disabled persons'.[27] On 7 December 1981 Princess Juliana, the former Queen of the Netherlands, spoke to the UN General Assembly on the occasion of the official closing of the International Year and underlined the moral obligation of welfare states to do their utmost to support other countries in their efforts to improve the often bad situation of people with disabilities.[28] The WPA, therefore, gave priority to developing nations since they 'have a bigger share of disability problems relative to

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[26] See my paper about the Dutch case 'Gelijkheid zonder beperking' (in review) and the PhD project of my Leiden colleague Anna Derksen about the IYDP in the Scandinavian context.

[27] United Nations, Commission for Social Development, Prevention of disability and rehabilitation of disabled persons, 19 December 1978 (E/CN.5/565), 5.

[28] Nationaal Archief Den Haag, Commissie Internationaal Jaar Gehandicapten (toegang 2.27.07), inventaris 10, speech Juliana.

the developed nations because of malnutrition and other poverty-related diseases, poor sanitation and lack of efficient communications systems'.[29]

It would be a misunderstanding if we interpreted the emphasis on development merely as a paternalistic attempt of the Global North to contribute to the development of the Global South. The WPA resonates with the ideal of global equality put forward by representatives of the Global South in the 1970s:

> problems of the disabled' were viewed as 'closely connected with overall development to a large extent on the creation of adequate international conditions for the faster socio-economic development of these countries. Accordingly, the establishment of the new international economic order is of direct relevance to the implementation of the objectives of the year.[30]

The reference to the New International Economic Order (1974) shows that disability in the WPA was framed into a broader vision of equality between countries and within societies. This framing does not, however, mean that disability became systematically included and mainstreamed in UN policies other than the disability policies of the Centre for Social Development and Humanitarian Affairs. That would only occur in the late 1990s.[31] Moreover, neither socio-economic equality nor socio-economic rights of people with disabilities were

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[29] United Nations, World Programme of Action.

[30] Ibidem.

[31] Shaun Grech, "Disability and Development: Critical Connections, Gaps and Contradictions", in *Disability in the Global South. The Critical Handbook,* ed. Shaun Grech and Karen Soldatic (Springer International Publishing Switzerland, 2016) 3-19; idem, "Disability and Poverty: Complex Interactions and Critical Reframings", 217-235.

central aims of the WPA. Instead, the assumption was that people with disabilities should experience equal advantage from their societies' development.[32]

The overarching aim of the UN - and the ECOSOC in particular - was therefore a structural change, although not focussing on disability alone. This scenario was thus significantly different from the (more restricted) notion of 'social change', which representatives of the Anglo-American model advocated. Moreover, organizations such as the WHO for which the medical model was still relevant were more influential at the UN level than activist organizations such as Disabled Peoples' International. It was for these reasons that rehabilitation and prevention could remain important points in the WPA and, as we will see later in this chapter, they would continue to remain a cornerstone of UN disability policies for a much longer period.

Nevertheless, we can observe another perspective on disability in the WPA under the heading of 'equalization' and focussing on anti-discrimination law:

> some countries have taken important steps to eliminate or reduce barriers to full participation. Legislation has in many cases been enacted to guarantee to disabled people the rights to and opportunities for schooling, employment and access to community facilities, to remove cultural and physical barriers and to proscribe discrimination against disabled persons.[33]

Overall, however, the emphasis was not on human rights and anti-discrimination. Inequality of disabled people for the purposes of the UN meant mainly inequality in living conditions

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[32] Cf. Moyn, *Not Enough*.

[33] United Nations, World Programme of Action.

and participation in society, which could be improved by services. The concept of equal rights played a role, but no real joint effort was undertaken to challenge member states to change their legislation or to develop new international legislation.

Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993)

Another key moment in the 'shift-narrative' from welfare to anti-discrimination and human rights is the formulation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993. Before taking a closer look at these rules, I will briefly discuss how disability rights were addressed during the UN Decade of Disabled Persons (1983-1992). One can observe increased attention to a human rights approach to disability at the UN during this decade. Next, to a broader reference to human rights as underlying principles of disability policies, human rights came to be used as a (international) yardstick for the maltreatment of people with disabilities.[34] Already in 1978 a WHO staff member, Einar Hollander, tried to convince the UN Commission on Human Rights that a special initiative was needed to address the maltreatment of people with disabilities and children in particular, but it would take a long time before this was picked up.[35] Only in 1984 did the Commission on Human Rights recommend to undertake a 'thorough study of the causal connection between serious violations of human rights and fundamental freedoms and

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[34] See for this distinction: Samuel Moyn, *Last Utopia. Human Rights in History* (Cambridge, MA/London: The Belknap Press of Harvard University Press, 2010)

[35] Einar Helander, "The Origins of Community Based Rehabilitation", *Behindering und internationale Entwicklung/ Disability and International Development* 24:1 (2013): 4-14: 11. Helander writes about the UN High Commissioner of Human Rights, but this institution did not exist at that time. Thanks to Sam de Schutter for suggesting me to read this paper.

disability as well as of the progress made to alleviate problems.' It took another couple of years before this study was carried out.[36]

  The idea of a human rights convention on disability was discussed officially for the first time during an expert meeting about the implementation of the World Program of Action in 1987 in Stockholm. On this occasion the relevant documents stated, far more explicitly than the WPA documents, that 'the basis of this guiding philosophy must be the recognition of the human rights of disabled persons, first as full citizens of their countries with the same rights as those of other citizens, and only secondary as users of social and other services'.[37] This did not mean that social services were not deemed important: 'social security systems providing services and support for disabled people and their families should be extended to allow disabled people to achieve their full potential in society'.[38] The experts, among whom people with disabilities were relatively well represented, recommended that:

> the General Assembly convene 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.[39]

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[36] Leandro Despouy, *Human Rights and Disabled Persons* (New York and Geneva: United Nations, 1993), https://www.un.org/esa/socdev/enable/dispaperdes0.htm.

[37] United Nations, Global Meeting of Experts to review the implementation of te World Programme of Action concerning Disabled Persons at the mid-point of the United Nations Decade of Disabled Persons [CSDMA/DDP/GME/7], 1 September 1987, 5.

[38] UN, Global meeting, 8.

[39] Ibidem, 6.

The governments of Italy and Sweden did submit proposals to the UN General Assembly in this direction in the years following the expert meeting but to no immediate avail.[40] The perspective that had determined the International Year of Disabled Persons was still dominant: the improvement of living conditions by social policy measures was seen as more urgent than realising a human rights convention.

The report initiated by the UN Commission on Human Rights and published in 1993 did not foster change in the reluctant attitude of the UN towards the drafting of a convention. In his report *Human Rights and Disabled Persons,* Leandro Despouy, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, observed that specific disability rights:

> do not appear in any formal listing but are scattered throughout a number of legal instruments, or have been recognized by the courts. In fact, what might be termed the specific rights of disabled persons are only the material and legal expression of the minimum contribution that the community or the State should make towards ensuring that such persons can enjoy on an equal basis all the human rights enjoyed by individuals in general.[41]

Despite all that was undertaken during the Decade of Disabled Persons, 'persons with disabilities are going to find themselves at a legal disadvantage in relation to other vulnerable groups such as refugees, women, migrant workers', and, 'unlike the other vulnerable groups,

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[40] United Nations, 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 [A/AC.265/2003/4], 2003, http://hr-travaux.law.virginia.edu/international-conventions/convention-rights-persons-disabilities.

[41] Despouy, *Human Rights*.

they do not have an international control body to provide them with particular and specific protection'. Therefore, Despouy stated that:

> the establishment of an international body or mechanism to supervise respect for the human rights of disabled persons is one of the most cherished aims of the non-governmental organizations.[42]

Leandro Despouy's report had a more narrow focus on human rights as a yardstick for the maltreatment of people with disabilities compared to the recommendation to draft a convention, as mentioned above, put forward by the experts in 1987. This did not immediately change the UN disability policies under responsibility of the ECOSOC, but the focus on human rights as a yardstick for maltreatment did gain significance when the idea of a convention was discussed in the early 2000s.

The developments during the decade indicate an increasing emphasis on a human rights-based approach. At the same time, they also reveal that the meaning of the concept was contested and that the concept represented only one of several that were used in the UN disability policies evolving during that time. Prevention, rehabilitation and development continued to remain highly relevant concepts, and 'with deep concern', a document did note 'that many developing countries are facing enormous difficulties in dealing with increasing numbers of disabled citizens'.[43]

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[42] Ibidem.

[43] United Nations, Draft resolution VII, United Nations Decade of Disabled Persons [E/1989/25, E/CN.5/1989/12], 15, http://hr-travaux.law.virginia.edu/international-conventions/convention-rights-persons-disabilities.

That a human rights approach to disability was not self-evident by the end of the decade also becomes obvious from the Standard Rules, the non-binding instrument on which the UN General Assembly ultimately reached agreement and one that was intended to promote 'disability-sensitive policy design and evaluation, as well as technical cooperation'.[44] In hindsight, the Rules represented an important step towards what became the UN Convention on the Rights of Persons with Disabilities in 2006. In the Rules, as legal scholars Quinn and Degener have stated, the 'traditional preoccupations of prevention and rehabilitation have been relegated to the background in favour of the rights perspective'.[45] However, if we take a closer look at the Rules, it is questionable if this really was the case.

The Rules document does state rather obviously that their purpose was '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'.[46] With this last phrase, the idea of a convention was deemed superfluous and ultimately excluded by the UN in 1993. Moreover, rights were framed as needs: 'the principle of equal rights implies that the needs of each and every individual are of equal importance'.[47]

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[44] UN, Views submitted.

[45] Gerard Quinn and Theresia Degener, *Human Rights and Disability. The current use and future potential of United Nations human rights instruments in the context of disability* (New York and Geneva: United Nations, 2002), 35, http://www.ohchr.org/Documents/Publications/HRDisabilityen.pdf (17 March 2018).

[46] United Nations, Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993, 5-6, https://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html.

[47] UN, Standard Rules, 8. Cf. Moyn, who shows in *Not Enough* how the human needs paradigm was used by the World Bank among others as a way to deal with (global) poverty without contesting material inequality structurally.

The Rules were about 'equalization of opportunities', and in that sense they built upon earlier policies that 'emphasized the right of persons with disabilities to the same opportunities as other citizens and to an equal share in the improvement in living conditions resulting from economic and social development'.[48] Furthermore, the situation of people with disabilities in developing countries was considered as urgent as before, and prevention and rehabilitation remained presented as 'fundamental concepts in disability policy'.[49] In contrast to suggestions from existing literature, there was thus a significant degree of continuity with earlier policies within the Rules. Human rights appeared to be interpreted in terms of needs and opportunities rather than in a legal sense of (status) equality, which is the dominant approach in the UN Convention on the Rights of Persons with Disabilities.

We can observe a certain degree of discontinuity on other issues. The Rules were for example covering more life domains than the World Programme of Action. Furthermore, the Rules more strongly underline the importance of the involvement of people with disabilities themselves. As well, the social model of disability was better integrated into the Rules than in earlier UN documents. This manifests in the section on terminology, which explains the need to recognize 'the necessity of addressing both the individual needs (such as rehabilitation and technical aids) and the shortcomings of the society (various obstacles for participation)'.[50] Thanks to the prevalence of the social model during the previous years, a topic such as accessibility received more attention than ever before. In comparison to the WPA, socio-economic equality was addressed more extensively in the Rules. Rule 7 was for example

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[48] Ibidem, 4.

[49] Ibidem, 6.

[50] Ibidem, 7.

concerned with the (human) right of employment while rule 8 informed states that they were 'responsible for the provision of social security and income maintenance for persons with disabilities'.[51] An important difference was that there were no longer any references to the New International Economic Order or to an alternative global vision of social justice.

  The Rules seemed, therefore, to constitute part of a broader shift in the UN and other international institutions away from a policy aimed at changing global inequality structures. The UN has had difficulties since the 1990s, according to Stefan-Ludwig Hoffmann, with responding to the increasing global discrepancy between rich and poor. Hoffmann exposes a major change in perspective: 'visual representations of the "Third World" have shifted from developing nations to suffering individuals, victims of natural or manmade disasters without political agency in the international arena'.[52] This statement does not hold entirely true for disability policies because self-advocates became increasingly involved in UN policies, and their role in the drafting of the UN Convention on the Rights of Persons with Disabilities is a unique phenomenon in international law making. At the same time, however, people with disabilities were often considered as one of the 'vulnerable groups' addressed in UN human rights policies – as we already observed in Despouy's report. In that sense, the framing of people with disabilities as a separate group in the world community that was explicitly vulnerable and deserved special attention was strengthened by the Rules (in which the

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[51] Ibidem, 17.

[52] Stefan-Ludwig Hoffmann, "Introduction. Genealogies of Human rights and history", in *Human Rights in the Twentieth Century* ed. idem (New York: Cambridge University Press, 2010), 24. Cf. Julia Dehm's blog "Rights as Potential Sites of Distributive Struggle", where she writes in response to Moyn's *Not Enough*: 'There was [in the late 1980s] a call for rights advocates to retreat from an ideal that "might call for equality for all" and instead focus on the pragmatic realization of rights through "consistent vigilance to improve the conditions for the most vulnerable, without expecting dramatic and abrupt transformations of comprehensive and interlocking economic and social systems"', see: https://tocqueville21.com/focus/rights-as-potential-sites-of-distributive-struggle/.

appointment of a special rapporteur was included). Different from the WPA, the Rules aimed at reaching an approach to disability that was all-encompassing but also tended to stand apart from other policies.

The Special Rules and the increasing attention to 'vulnerable groups' in the 1990s can explain the decision of the UN General Assembly to support Mexico's proposal in 2001 to develop a special convention on the rights of people with disabilities. With the international convention, the UN disability policies finally became rights-based, but this development can hardly be seen as an uncontested endpoint. Already at the stage of the negotiations, critics expressed the concern that disability was insufficiently integrated into the Millennium Development Goals.[53] The convention is, moreover, increasingly criticized from a Global South perspective with socio-economic inequality and poverty being the main concerns. This begs the question of whether:

> a redistribution of power and wealth both between rich and poor countries and within
> poor countries could have more impact on the lived experience of disabled people in
> the global South than would human rights legislation.[54]

These remarks are not intended to deny the worldwide progress in the last decades towards ensuring equality and equal rights of persons with disabilities. Rather, they are intended to call attention to how complicated this trajectory of progress was and still is.

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[53] United Nations, General Assembly 60th Summary record of the 5th meeting 3rd committee, 2005 (A/C.3/60/SR.5), http://hr-travaux.law.virginia.edu/international-conventions/convention-rights-persons-disabilities. In 2001 the 'argument for a disability convention was framed in light of the recently released Millenium Development Goals' by Mexico, see Heyer, *Rights enabled*, 172-173.

[54] Helen Meekosha and Karen Soldatic, "Human Rights and the Global South: the case of disability", *Third World Quarterly* 32, 8 (2011): 1383-1397: 1389.

Conclusion

The current debates among disability experts on the limited use or even uselessness of the human rights framework in the Global South reflect the broader discussion about global economic inequality and the critical evaluation of the attention to other types of inequalities that have become prominent in recent decades, most notably, status inequality. I have shown in this chapter that what the research literature has described as a shift in global disability policies and the global disability movement from welfare to human rights since the 1970s is much more complex and contentious than often suggested. A closer look at disability protests and movements worldwide has demonstrated that welfare and economic inequality did not necessarily lose importance with the introduction of a human rights perspective on disability. Based on the investigation of two key moments in UN disability policy, the International Year of Disabled Persons (and WPA) in 1981 and the Standard Rules on Equalization of Opportunities for Persons with Disabilities in 1993, I have shown that the human rights perspective on disability was far from self-evident or dominant until the UN decided to develop a convention in 2001. Disability around the year 1981 was mainly conceptualized as a development issue and as part of NIEO policies. This assumed that people with disabilities would and should have advantage of global equality as envisioned in the NIEO. This vision was almost absent in 1993: the Rules as adopted by the UN in that year reflected an increasing attention to 'vulnerable groups' in development and human rights policies. The focus on 'vulnerability' did not so much reflect the concern with structural socio-economic inequalities. Rather, such an approach was meant to ensure 'that the needs [and opportunities] of each and every individual are of equal importance'. Therefore, the presumed shift from welfare to human rights in global disability policy during the 1980s could perhaps be better

understood as a shift to human needs, followed by a shift – although contested from the start - to human rights in the late 1990s.

The analysis of international disability policies does inform the larger debate on global inequality in at least two ways. Firstly, it suggests a more complex chronology: attention to socio-economic inequality was not waning since the 1970s as is suggested in the literature. Only in the 1990s, socio-economic inequality came to be seen as less urgent and a human needs approach began to become dominant. Global inequality seems to have multiple chronologies. Secondly, my analysis sheds new light on the supposed relation between the increasing attention to status inequality and the neglect of material inequality. During the 1990s the situation of 'vulnerable groups' like people with disabilities came to be seen as a policy area in itself and was approached less as part of a general policy aimed at changing global inequality structures. However, the increasing attention to the status equality of 'vulnerable groups' did not mean that economic inequality necessarily lost importance. Human rights even kept the door open for addressing socio-economic inequalities: the Convention on the Rights of Persons with Disabilities for instance, includes socio-economic rights and is compared to other international law sensible to 'issues of structural power and oppression'.[55] The future will learn if human rights live up to this potential.

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[55] Frédéric Mégret, "The disabilities convention: Human rights of persons with disabilities or disability rights?", *Human Rights Quarterly* 30, 2 (2008): 494-516.