

A Global Monitoring Practice in the Making

Disability Measurement for UN Sustainable Development Goal 4 on Inclusive Education

Abstract: In this paper, we examine a global assessment practice in the making: the measurement procedures proposed by the international community to monitor the Sustainable Development Goals (SDGs). Our focus is on SDG 4, which requires UN member states to ensure inclusive education systems in order to realise the right to education for *all*, including persons with disabilities. To identify persons with disabilities, a global disability measure was introduced: the Washington Group Questions (WGQ). In line with the human rights norm of inclusion, the WGQ aim to reflect a social model of disability. We explore this claim based on a Sociology of Knowledge Approach to Discourse combined with insights from Disability Studies. To this end, we show first, how a social model approach to disability was developed by the international community regarding the human right to education, and, secondly, how this approach is supposed to be applied in disability measurements for the monitoring of SDG 4. Based on our analysis, we will argue that the WGQ do not fully capture a social model of disability yet; instead, they introduce a social model of impairment. Even though these measurements increase the visibility of persons with disabilities in the monitoring of SDG 4, they do not yet allow to comprehensively identify the barriers disabled persons face in realising their right to education.

Keywords: Sustainable Development Goals (SDGs), United Nations, inclusive data, disability measurement, global development indicators, inclusive education, human rights monitoring

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Introduction

Since its establishment on 24 October 1945, the United Nations (UN) has become the key global actor in promoting and monitoring the realisation of human rights. For this purpose, the international organisation and its experts gather and evaluate information on the living conditions of people around the world. This information is based on measurements, for instance of population categories and education.¹ Measurements determine the dimensions, capacities as well as the extent of developments in UN member states; they, for example, provide the database for the evaluation and the subsequent assessment of countries' progress in realising human rights, both nationally and internationally.²

In recent years, human rights monitoring practices started to change, particularly in response to the Sustainable Development Goals (SDGs). Having brought into force in 2016, the SDGs are a global development agenda to promote ecological, economic and social changes in all UN member states by 2030.³ Guided by the principle of 'leaving no one behind', the focus of the SDGs has shifted to groups most vulnerable to exclusion and marginalisation in all areas of social life, such as people with disabilities.⁴ In terms of education, SDG 4 specifies that countries have to "ensure inclusive and equitable quality education and promote lifelong learning opportunities for all" in order to increase the participation of disabled persons.⁵ To monitor countries' progress in achieving this goal at the international level, the realities of education must be observed at national and local levels, for example, regarding school enrolment and completion as well as abstentions and early dropouts.⁶ For that reason, the UN require member states to produce inclusive data – disaggregated by gender, location, socio-economic background and disability status.⁷

1 See Rainer Diaz-Bone/Emmanuel Didier, *The Sociology of Quantification – Perspectives on an Emerging Field in the Social Sciences*. in: *Historical Social Research* 4/2 (2016), 7–26.

2 See Richard Rottenburg/Sally E. Merry, *A World of Indicators. The Making of Governmental Knowledge through Quantification*, in: Richard Rottenburg et al. (eds.), *The World of Indicators. The Making of Governmental Knowledge through Quantification*, Cambridge 2015, 1–33.

3 UN Doc. A/RES/70/1.

4 UN, *Leaving No One Behind: The Imperative of Inclusive Development*. Report on the World Social Situation, New York 2016, <https://www.un.org/esa/socdev/rwss/2016/full-report.pdf> (10.6.2020); see also Karin Arts, *Inclusive Sustainable Development. A Human Rights Perspective*, in: *Current Opinion in Environmental Sustainability* 24 (2017), 58–62.

5 UN, *Sustainable Development Goal 4 – Targets and Indicators*, 2020, <https://sustainabledevelopment.un.org/sdg4> (10.6.2020).

6 *Ibid.*; UNESCO Institute for Statistics, *Laying the Foundation to Measure Sustainable Development Goal 4*, Montreal 2016, <http://uis.unesco.org/sites/default/files/documents/laying-the-foundation-to-measure-sdg4-sustainable-development-data-digest-2016-en.pdf> (10.6.2020).

7 Global Partnership for Sustainable Development Data, *Inclusive Data Charter*, 2018, <http://www.data4sdgs.org/initiatives/inclusive-data-charter> (10.6.2020); Daniel Mont, *Disaggregating the Sustainable*

This data must now be collected, compiled and evaluated by experts in administration, politics and science, both at national and international level; and this based on global indicators as well as coordinated models and classifications of disability.⁸

Until today, however, only limited datasets are available on persons with disabilities that would allow to systematically assess and compare their participation in education within and across countries. This is because disabled persons are still overwhelmingly marginalised in most societies and therefore also often not included in statistics.⁹ In addition, perceptions of disability are ultimately tied to specific, historically shaped socio-economic, cultural and educational contexts.¹⁰ Accordingly, the UN cautions: “Due to differences in the concepts and methods used to identify persons with disabilities, prevalence rates should not be compared across countries.”¹¹ For identifying persons with disabilities in an internationally comparable way, the UN therefore promotes a global disability measure: the so-called Washington Group Questions (WGQ).¹²

The intricate link between disability data and human rights monitoring for inclusive education has not yet been in the focus of research. There are studies on the appropriateness of global indicators to assess whether and to what extent SDG 4 is implemented¹³ and on practical experiences of using the WGQ.¹⁴ What remains under-

Development Goals by Disability. To Leave No One Behind, in: *Behinderung und internationale Entwicklung* 30/2 (2019), 11–15.

- 8 UN, Sustainable Development Goal 4, 2020; UN, Realization of the Sustainable Development Goals by, for and with persons with disabilities. UN Flagship Report on Disability and Development, New York 2018, <https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2018/12/UN-Flagship-Report-Disability.pdf> (10.6.2020).
- 9 World Health Organization [WHO]/World Bank, *World Report on Disability*, Geneva 2011.
- 10 See Marguerite Schneider, *Cross-National Issues in Disability Data Collection*, in: Barbara Altmann (ed.), *International Measurement of Disability, Purpose Method and Application*, Basel 2016, 15–28; Mont, *Disaggregating*, 2019, 11.
- 11 UN, *Towards Further Improvements in Disability Statistics. Joint Statement by UNSD and the Washington Group*, 2017, <https://unstats.un.org/unsd/demographic-social/sconcerns/disability/WG%20UNSD%20Joint%20Statement.pdf> (10.6.2020).
- 12 Washington Group, *Disability Measurement and Monitoring using the Washington Group Disability Questions*, 2018, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/732254/Disability-Measurement-Monitoring-Washington-Group_-_Disability-Questions.pdf (10.6.2020).
- 13 See Elaine Unterhalter, *The Many Meanings of Quality Education. Politics of Targets and Indicators in SDG4*. in: *Global Policy* 10/1(2019), 39–51, doi: 10.1111/1758-5899.12591; Kenneth King, *Lost in Translation? The Challenge of Translating the Global Education Goal and Targets into Global Indicators*, in: *Compare. A Journal of Comparative and International Education* 47/6 (2017), 801–817, doi: 10.1080/03057925.2017.1339263.
- 14 See Annie Sloman/Melina Margaretha, *The Washington Group Short Set of Questions on Disability in Disaster Risk Reduction and Humanitarian Action. Lessons from Practice*, in: *International Journal of Disaster Risk Reduction* 31 (2018), 995–1003; Kirsten Miller, *Summary of Washington Group Question Evaluation Studies*, in: Barbara Altmann (ed.), *International Measurement of Disability, Purpose Method and Application*, Basel 2016, 69–84.

explored are the approaches to disability in the context of human rights and their monitoring. This is a crucial research gap as the norm of inclusion requires data that does not measure disability based on medical notions of impairment alone. Instead, data must – in line with the UN Convention on the Rights of Persons with Disabilities – indicate how impairments interact “with various barriers [that] may hinder [the] full and effective participation in society on equal basis with others”.¹⁵ This obligation implies a twofold challenge for the generation of inclusive data: first, context-specific relationships between impairment and social environment must be outlined; secondly, this needs to be done in an internationally comparable fashion. For the monitoring of SDG 4, the crucial question is therefore: how is disability conceptualised in the context of the human right to education?

To engage with this question, we first explore how a relational approach to disability – focusing on the interaction between impairment and environment – has evolved historically in the realm of the human right to education. Secondly, we show how this approach is reflected in data collection when using the WGQ. This analysis makes the institutionalisation of a global assessment practice transparent; it exemplifies “the development and proliferation of [a] more and more sophisticated measurement and quantification system” of disability, and how the knowledge it produces “influences the ways we set the norms we wish to follow”.¹⁶

The disability knowledge enshrined in the human rights norm of inclusion and the WGQ is the object of our analysis, not the network of national and international actors that re-/ produce this knowledge in order to monitor access and participation in education.

For this analysis, we combine a Sociology of Knowledge Approach to Discourse with insights from Disability Studies. Discourses generate knowledge about disability.¹⁷ This knowledge instructs and legitimises actions such as the measurement of disability for human rights monitoring. Empirically, we are going to reconstruct this knowledge by showing how disability is understood, i.e. classified, in historical UN documents on the human right to education as well as in the WGQ, the proposed measurement for generating globally comparable disability data. To reflect on this disability knowledge, we tap into the field of Disability Studies, which advances the academic discussion about disability as a socially constructed reality.¹⁸

This analysis will show that the translation of a social model approach to disability into the human rights norm of inclusion was successful. However, it is not yet

15 UN Doc. A/RES/61/106, Article 1.

16 Rottenburg/Merry, *World*, 2015, 2.

17 See also Shelly Tremain (ed.), *Foucault and the Government of Disability*, Ann Arbor MA 2005.

18 Lisa Pfahl/Justin J.W. Powell, *Subversive Status. Disability Studies in Germany, Austria and Switzerland*, in: *Disability Studies Quarterly* 34/2 (2014), n.p., doi: 10.18061/dsq.v34i2.4256.

fully reflected in the measurement of disability for human rights monitoring as the WGQ introduce a social model of impairment. In this way, the requirement to produce inclusive data strengthens the recognition of persons with disabilities as holders of human right to education but does not allow to comprehensively identify the barriers disabled persons face in realising this right.

To develop this argument, we show how critical disability knowledge has contributed to the UN human rights discourse on inclusive education. We then highlight the consequences of disability-disaggregated data for the formalisation of a global monitoring practice as well as the realisation of the right to inclusive education for persons with disabilities.

Analysing Disability Knowledge: Global Norms, Classifications & Measurements

Inclusive education has become a global human rights challenge over the past decades. Having committed to the SDGs in 2015, UN member states are now under more pressure than ever to “ensure inclusive and equitable quality education [...] for all” (SDG 4).¹⁹ Accordingly, they need to “ensure equal access to all levels of education [...] for the vulnerable, including persons with disabilities” (SDG 4.5).²⁰ To meet this target, countries are tasked to “build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all” (SDG 4.a).²¹ In order to monitor countries’ progress towards achieving SDG 4, the international community has introduced global indicators. These include “parity indices (female/male, rural/urban, bottom/top wealth quintile and others such as disability status, indigenous peoples and conflict-affected)” (SDG 4.5.1) as well as the “proportion of schools with access to: [...] adapted infrastructure and materials for students with disabilities” (SDG 4.a.1).²²

As the collection of comparable, disability-disaggregated education data is getting increasingly important, there is an urgent need to comprehend the procedures of modelling and classifying disability for human rights monitoring. This is because any dataset entails “abstract statements that have been removed from their context and written down one after another as facts”, while the “classification system and

19 UN, Sustainable Development Goal 4, 2020.

20 Ibid.

21 Ibid.

22 Ibid.; see also UN, Interagency and Expert Group on SDG Indicators, 2020, <https://unstats.un.org/sdgs/iaeg-sdgs/> (10.6.2020); UN, Tier Classification for Global SDG Indicators, 2020, <https://unstats.un.org/sdgs/iaeg-sdgs/tier-classification/> (10.6.2020).

selection principle according to which the facts [...] are chosen are not included in the list[s]”²³ For this reason, the ‘disability knowledge’ generated in UN discourses on the right to education and its monitoring is an important research object on which we focus in our analysis.

Knowledge entails symbolic orders that affirm adequate and appropriate descriptions and perceptions of the world, and in this case disability.²⁴ Over time, meaningful knowledge solidifies into classifications that, once “institutionalized”, are “erroneously viewed as being a characteristic of the thing itself”²⁵ By this means, socially produced meanings become an outside facticity, empowering and controlling future actions, such as the measurement of disability for human rights monitoring. All of this occurs in and through discourses – regulated practices of knowledge production within and through which the world can be known.²⁶ In discourses on human rights and their monitoring, the international community generates, deliberates and/or legitimises ideas about the measurement of disability.²⁷ For this reason, “discursive processes alone help explain why certain ideas succeed and others fail”²⁸ Against this backdrop, we understand the relation between a social model approach to disability and SDG4-monitoring as depending on the knowledge that policy actors re-/produce in discourses which lead to and emanate from SDG 4.

For the reconstruction of this disability knowledge, we use a Sociology of Knowledge Approach to Discourse²⁹ informed by Disability Studies.³⁰ Based on this approach, we focus analytically on the discursive processes of symbolic ordering. Insights into these can be gained by showing how disability is classified in UN discourses on the human right to education and its monitoring.³¹ In general, classifications are at the heart of social life; they organise and structure insights into the social world and can thus be understood as “set[s] of boxes (metaphorical or literal) into which things can be put to then do some kind of work – bureaucratic work or knowledge production.”³² With regard to disability, classification systems

23 Richard Rottenburg, *Far-Fetched Facts. A Parable of Development Aid*, Cambridge, MA 2009, 137.

24 Reiner Keller, *The Sociology of Knowledge Approach to Discourse (SKAD)*, in: *Human Studies* 34/1 (2011), 43–65.

25 Rottenburg, *Far-Fetched Facts*, 2009, 137.

26 Michel Foucault, *The Archaeology of Knowledge*, London 2002 [1969], 49, 201.

27 See Vivien A. Schmidt, *Taking Ideas and Discourse Seriously*, in: *European Political Science Review* 2/1 (2010), 1–25.

28 Vivien A. Schmidt, *Discursive Institutionalism. The Explanatory Power of Ideas and Discourse*, in: *Annual Review of Political Science* 11/1 (2008), 303–326, 309.

29 Keller, *Sociology*, 2011; idem, *Wissen oder Sprache? Für eine wissensanalytische Profilierung der Diskursforschung*, in: *Österreichische Zeitschrift für Geschichtswissenschaften* 6/4 (2005), 7–47.

30 Jan Grue, *Disability and Discourse Analysis*, Farnham/Burlington 2015.

31 Schmidt, *Discursive Institutionalism*, 2008, 304.

32 Geoffrey C. Bowker/Susan Leigh Star, *Sorting Things Out. Classification and Its Consequences*, Cambridge, MA 1999, 2, 10.

are required to determine who belongs to the population of persons with disabilities and who does not.³³ In this way, classification systems draw symbolic boundaries; they make differences visible between groups of people regarded either as disabled, impaired or healthy. Disability classifications thus are powerful institutional tools; they are the 'social place' where knowledge is generated, which, in turn, instructs and legitimises the measurement of disability for human rights monitoring.

In the following section, we empirically explore the disability knowledge entailed in UN documents on the right to education and in the WGQ. Specifically, we will reconstruct how approaches to disability in the human rights context of education have historically evolved and are currently applied.

The Human Rights Discourse on Inclusive Education: Changing Models of Disability

With the SDGs, the local collection and global distribution of disability-disaggregated education data has become an international requirement for human rights monitoring. What were the reasons for this development, and how did the disability rights movement contribute to it? To answer these questions, we focus on the historical evolution of approaches to disability within the UN system over the last seven decades and analyse statements on impairment and disability in UN documents on the right to education. In doing so, three historical phases are distinguished: from the mid-1940s to the 1960s, there was silence on the right to education for persons with disabilities; from the 1970s to the 1990s, the right to education for persons with disabilities was generally recognised and since the 2000s, the human right to inclusive education for persons with disabilities has been acknowledged. Focusing on major developments reflected in UN documents, different approaches to disability are identified and related to discussions about disability models in the field of Disability Studies.

33 See also Julia Biermann/Lisa Pfahl, Die Bedeutung sonderpädagogischer Klassifikationssysteme für das Recht auf inklusive Bildung, in: *Bildung und Erziehung: Inklusive Bildung* 4 (2018), 432–448.

Table 1: Historical Phases of the Human Rights Discourse on Inclusive Education

Year	UN Documents	Disability Reference	Disability Model
Mid-1940s–1960s: Silence on the Right to Education for Persons with Disabilities			
1948	Universal Declaration of Human Rights	No references to disability or impairment	Medical model
1966	International Covenant on Economic, Social and Cultural Rights		
1970s–1990s: Recognition of the Right to Education for Persons with Disabilities			
1975	Declaration on the Rights of Disabled Persons	Disability as impairment	Shift from medical to social model
1981	International Year of Disabled Persons		
1983–1992	Decade of Disabled Persons		
1989	Convention on the Rights of the Child		
1993	Standard Rules on the Equalization of Opportunities for Persons with Disabilities		
1994	Salamanca Statement and Framework for Action		
2000	Dakar Framework for Action		
2000	Millennium Development Goals		
Since 2000s: Acknowledgement of the Human Right to Inclusive Education for Persons with Disabilities			
2001	International Classification of Functioning, Disability and Health	Disability as interaction between impairment and environmental barriers	Shift from social to human rights model
2006	Convention on the Rights of Persons with Disabilities		
2015	Incheon Declaration		
2016	Sustainable Development Goals		

Mid-1940s to 1960s: Silence on the Right to Education for Persons with Disabilities

In 1948, the Universal Declaration of Human Rights affirmed that “everyone has the right to education”, which “shall be free” and “compulsory” at the elementary stages;³⁴ a right further strengthened in the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR).³⁵ Despite these universal claims, neither of the documents refers to disability. In fact, it was only in 1994 when the UN Committee on Economic, Social and Cultural Rights, monitoring the ICESCR implementation, requested in its General Comment No. 5 “to ensure the full enjoyment of the relevant rights [of this Covenant] by persons with disabilities”.³⁶ The main reason for this silence was that people with disabilities were primarily perceived as bodily and mentally impaired and thus as objects of rehabilitation and care. Accordingly, they were positioned outside the realm of human rights.³⁷ The UN human rights discourse from the 1940s to the 1960s can therefore be characterised as apolitical in relation to disability; apart from charity actions, little attention has been paid to the participation of persons with disabilities in social and public life. From a Disability Studies perspective, this phase reflects the dominance of a medical model of disability. Disability was understood as an individual deficit, a bodily impairment requiring the expertise of medical, psychological and special pedagogical professions.³⁸

1970s to 1990s: Recognition of the Rights of Persons with Disabilities

The first official UN document recognising the entitlement of persons with disabilities to human rights was the 1975 Declaration on the Rights of Disabled Persons.³⁹ This document contributed to a growing awareness about the marginalisation of persons with disabilities within societies, and ultimately the human rights framework. As a result, the UN proclaimed 1981 the International Year of Disabled Persons, with the theme “full participation”,⁴⁰ which was later expanded to “full participation and equality”.⁴¹ The International Year’s aim was “helping disabled

34 UN Doc. A/RES/217[III], Article 26, para. 1.

35 UN Doc. GA/RES/2200 A [XXI], Article 13.

36 UN Doc. E/1995/22, para. 2.

37 Gerard Quinn/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/Geneva 2002, 23–26.

38 Katharina Heyer, *Rights Enabled. The Disability Revolution, from the US, to Germany and Japan, to the United Nations*, Ann Arbor MA 2015, 24–27, 170.

39 UN Doc. A/RES/30/3447.

40 UN Doc. A/RES/31/123.

41 UN Doc. A/RES/34/154, para. 1.

persons in their physical and psychological adjustment to society” and “[p]romoting effective measures for the prevention of disability and for the rehabilitation of disabled persons”.⁴² The subsequently introduced World Programme of Action concerning Disabled Persons was to be implemented during a Decade of Disabled Persons from 1982 to 1993.⁴³ The implementation of the 1993 Standard Rules on the Equalisation of Opportunities for Persons with Disabilities concluded the decade.⁴⁴ This document was crucial in strengthening a human rights approach to disability; it led to the appointment of a Special Rapporteur on Disability⁴⁵ and added the principle of equal opportunity to the principles of prevention and rehabilitation.⁴⁶ In terms of education, the Standard Rules stipulated accordingly that “states should recognize the principle of equal [...] educational opportunities for children [...] with disabilities, in integrated settings”, that is to “aim for the gradual integration of special education services into mainstream education”.⁴⁷

As the implementation of the right to education for persons with disabilities, however, faced serious challenges globally, efforts at the UN level increased, as evidenced in the 1989 UN Convention on the Rights of the Child (UN CRC).⁴⁸ Article 23 UN CRC focuses exclusively on disabled children and requires state parties to recognise their “special needs” and ensure that they have “effective access to and receive education”.⁴⁹ Contemporaneous to the UN CRC, the global Education for All (EFA) movement introduced a similar approach: “learning needs of the disabled demand special attention” and require “steps [...] to provide equal access to education to every category of disabled persons as an integral part of the education system”.⁵⁰ In 1994, the World Conference on Special Needs Education supplemented this requirement by heralding inclusive education as the guiding principle to realise EFA. Anchored in the Salamanca Statement and Framework for Action, this prin-

42 UN Doc. A/RES/31/123, lit. 2a, e.

43 UN Doc. A/RES/37/52.

44 UN Doc. A/RES/48/96.

45 The Special Rapporteur on Disability was affiliated to the Commission of Social Development, a standing Committee of UN’s Economic and Social Council (ECOSOC). From 1994 to 2015, the Special Rapporteur on Disability issued an annual report about the Monitoring of the Implementation of the Standard Rules.

46 See also Bengt Lindqvist, Standard Rules in the Disability Field. A New United Nations Instrument, in: Theresia Degener/Yolan Koster-Dreese (eds.), *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments*, Dordrecht 1995, 63–68.

47 UN Doc. A/RES/48/96, Rule 6, preamble, para. 8.

48 UN Doc. A/RES/44/25; see also Thomas Hammarberg, The Rights of Disabled Children. The UN Convention on the Rights of the Child, in: Degener/Koster-Dreese, *Human Rights*, 1995, 147–155.

49 UN Doc. A/RES/44/25, para. 3, also 2.

50 World Conference in Education for All, World Declaration on Education for All and Framework for Action to Meet Basic Learning Needs, 1990, Art. 3, para. 5, <https://unesdoc.unesco.org/ark:/48223/pf0000085625> (10.6.2020).

principle states “schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions”.⁵¹ In formulating this vision, the Salamanca Statement draws on the 1993 Standard Rules that urged states “to ensure that the education of persons with disabilities is an integral part of the education system”.⁵²

Far from having achieved the goal of EFA, the international community reconvened in 2000 for the World Education Forum and agreed on six EFA goals to be achieved by 2015, including the provision of free and compulsory primary education. The resulting Dakar Framework for Action thus encourages states to “develop [...] ‘inclusive’ education systems which explicitly identify, target and respond flexibly to the needs and circumstances of the poorest and the most marginalized”.⁵³ In addition, the UN General Assembly adopted the Millennium Development Goals in 2000 that pursued universal primary education to be achieved by 2015.⁵⁴ With these provisions, the EFA movement contributed to the formation of inclusive education as a key strategy to ensure equal access to and participation in education. The UN human rights discourse between the mid-1970s and the 1990s thus reflects a shift from a medical to a social model of disability, highlighting the need for structural and pedagogical changes to accommodate the needs of disabled children in regular education settings.

This shift was actively promoted by the international disability movement, which accompanied developments in the realm of human rights to fight for independent living and equal participation since the late 1970s. A ground breaking document in this context was released by the UK-based Union of the Physically Impaired Against Segregation (UPIAS) in 1976 titled the Fundamental Principles of Disability. It states: “Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society.”⁵⁵ Thus, disability is considered here as a form of oppression which emerges from traditional disability care systems excluding disabled persons from mainstream society, supposedly for their own good, but with fatal consequences such as isolation, discrimination

51 World Conference on Special Needs Education, The Salamanca Statement and Framework for Action on Special Needs Education, 1994, 6, para. 3, <https://unesdoc.unesco.org/ark:/48223/pf0000098427?posInSet=4&queryId=5c78bc0c-9700-4162-80a9-7b7496eddbd9> (10.6.2020).

52 Ibid., preamble.

53 World Education Forum, The Dakar Framework of Action. Education for All: Meeting our Collective Commitment, 2000, 18, para. 52, <https://unesdoc.unesco.org/ark:/48223/pf0000120240?posInSet=2&queryId=61878c11-7faa-495e-9db0-ad6ea4308b44> (10.6.2020).

54 UN Doc. A/RES/55/2.

55 Union of the Physically Impaired Against Segregation/The Disability Alliance, Fundamental Principles of Disability, London 1976, 3–4.

and stigmatisation.⁵⁶ Similarly, activists and scholars outside the UK started to challenge traditional medical-oriented approaches to disability.⁵⁷ They advocated a shift in focus away from individuals' deficits towards socially constructed barriers that limit equal access and participation, including in education. In Germany, for example, the disability movement staged a so-called 'cripple tribunal' in 1981 to draw attention to human rights violations resulting from forcing people with disabilities into special kindergartens, schools, homes and workplaces.⁵⁸ Following the civil rights movement, activists and scholars in the US were spearheading a rights approach to disability. They waged a cultural struggle, demanding to recognise persons with disabilities as a minority group.⁵⁹ Despite these international efforts, the social rights or minority approach to disability could not be established. Education systems around the world continued to exclude or segregate children with disabilities in special schools.⁶⁰ As the principles of integration and inclusion were only taken up slowly, if at all, the international disability movement and community increased their efforts to codify inclusion as a human rights norm.⁶¹

Since 2000s: Acknowledgement of the Human Rights of Persons with Disabilities

In 2006, the rights of persons with disabilities were finally officially acknowledged with the UN Convention on the Rights of Persons with Disabilities (UN CRPD).⁶² Broadening the UN's human rights architecture, this international treaty constitutes a new phase in the institutionalisation of a rights-based approach to disability.⁶³

The UN CRPD reaffirms that all persons with disabilities must enjoy all human rights and fundamental freedoms. In addition, it adopts a broad understanding of persons with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder

56 For example Vic Finkelstein, *Attitudes and Disabled People. Issues for Discussion*, New York 1980; Irving K. Zola, *Missing Pieces. A Chronicle of Living with a Disability*, Philadelphia 1982; Len Barton/Sally Tomlinson (eds.), *Special Education and Social Interests*, London 2012 [1984]; Michael Oliver, *The Politics of Disablement*, Basingstoke 1990.

57 Pfahl/Powell, *Subversive Status*, 2014.

58 Swantje Köbsell, *Towards Self-Determination and Equalization. A Short History of the German Disability Rights Movement*, in: *Disability Studies Quarterly* 26/2 (2006), n.p., <https://dsq-sds.org/article/view/692/869>; also Heyer, *Rights*, 2015, 96.

59 *Ibid.*, 55–62.

60 Justin J.W. Powell, *Barriers to Inclusion. Special Education in the United States and Germany*, Boulder 2011; John Richardson/Justin J.W. Powell, *Comparing Special Education. Origins to Contemporary Paradoxes*, Stanford 2011.

61 Quinn/Degener, *Human Rights*, 2002.

62 UN Doc. A/RES/61/106.

63 Heyer, *Rights*, 2015, 168.

their full and effective participation in society on an equal basis with others”⁶⁴ With this definition, the UN CRPD incorporates a social model approach to disability into the human rights canon. This approach comes with an important implication for the meanwhile 181 state parties;⁶⁵ it requires to actively remove social barriers that impede the participation of persons with disabilities on equal basis with others. In terms of education, Article 24 specifies that this entails to ensure inclusive education systems at all levels, necessitating to overcome disability-based exclusions as well as segregation in special education systems.⁶⁶ Effectively, Article 24 UN CRPD thus transforms the right to education into a right to inclusive education.⁶⁷ The World Education Forum confirms this development in its 2015 Incheon Declaration, which promotes “a single, renewed education agenda that is holistic, ambitious and aspirational, leaving no one behind”⁶⁸ This commitment supports the implementation of the 2030 Agenda for Sustainable Development, in particular Sustainable Development Goal 4.⁶⁹ Against this background, the need for reliable disability data – the generation of which is an obligation under Article 31 UN CRPD – has been increasingly addressed in various UN documents; for example by the General Assembly⁷⁰ and the Economic and Social Council.⁷¹

In light of these developments, the UN human rights discourse on education that started in the 2000s can be characterised as pivotal for the codification of inclusion as a human rights norm. Based on this norm, disability must be understood as a social phenomenon that is informed by the interplay of individual impairments and social environments. By this means, a social model of disability is established within the realm of human rights. Rather than considering individual impairments as the prime impediments to equal participation, this model puts its primary emphasis on the barriers arising in and from the organisational, structural and legal realities of education. This shift has sparked far-reaching and controversial debates about the

64 UN Doc. A/RES/61/106, Article 1.

65 UN, Convention on the Rights of Persons with Disabilities, 2020, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (10.6.2020).

66 UN Doc. CRPD/C/GC/4, para. 11.

67 Gauthier de Beco, Transition to Inclusive Education Systems According to the Convention on the Rights of Persons with Disabilities, in: *Nordic Journal of Human Rights* 34/1 (2016), 40–59.

68 World Education Forum, Incheon Declaration and Framework for Action for the implementation of Sustainable Development Goal 4, 2016, para. 5, http://uis.unesco.org/sites/default/files/documents/education-2030-incheon-framework-for-action-implementation-of-sdg4-2016-en_2.pdf (10.6.2020).

69 UN Doc. A/RES/70/1; also UN, Leaving No One Behind: The Imperative of Inclusive Development. Report on the World Social Situation, 2016, <https://www.un.org/esa/socdev/rwss/2016/full-report.pdf> (10.6.2020); see also Heloise Weber, Politics of ‘Leaving No One Behind’: Contesting the 2030 Sustainable Developmental Goals Agenda, in: *Globalizations* 14/3 (2017), 399–414.

70 UN Doc. A/RES/65/186; A/65/173; A/64/180; A/RES/60/121; A/RES/54/121.

71 UN Doc. E/RES/2012/11; E/CN.5/2011/9.

extent and scope of consequent educational changes in member states.⁷² The UN discourse has thus fostered awareness on the topics of inclusion, equal participation and non-discrimination. In addition, it set new standards for the monitoring of human rights. To this end, the UN promote the collection of disability data based on the Washington Group Questions (WGQ).⁷³ In the next section, we focus on the ‘disability knowledge’ enshrined in the WGQ to answer the question of how disability is conceptualised in the context of human rights monitoring.

The Washington Group Questions: The Global Disability Measurement Tool

The Washington Group Questions (WGQ) were developed by the Washington Group on Disability Statistics, established in 2001 under the United Nations Statistical Commission.⁷⁴ Its members are representatives from national statistical commissions, so far of over 135 countries.⁷⁵ The group has developed a so-called Short Set on Questions of Disability (WG SS, see box below), which has been tested in over 60 countries.⁷⁶ These questions ask about the degree of difficulties people from the age of five experience in seeing, hearing, walking, cognition, self-care and communication. Their aim is to “identify persons with similar types and levels of limitations in basic actions regardless of nationality or culture”.⁷⁷ It is understood that these limitations “put them *at risk* of not being able to participate, for example to go to work or school, in an unaccommodating environment”.⁷⁸ In this way, the WGQ try to depict

72 See Julia Biermann, „Sonderpädagogisierung der Inklusion“, Artikel 24 UN-BRK und die Diskurse über die Entwicklung inklusiver Schulsysteme in Nigeria und Deutschland, in: *Aus Politik und Zeitgeschichte* 69/6–7 (2019), 19–23.

73 For example Secretariat to the Convention on the Rights of Persons with Disabilities/UNESCO, United Nations Expert Group Meeting on Disability Data and Statistics, Monitoring and Evaluation: The Way Forward – a Disability Inclusive Agenda Towards 2015 and Beyond, Paris, France (8–10 July 2014), Report, 2014, 6, https://www.un.org/disabilities/documents/egm2014/EGM_FINAL_08102014.pdf (10.6.2020).

74 Washington Group, About the WG, 2020, <https://www.washingtongroup-disability.com/about-the-wg/> (5.11.2020).

75 Washington Group, Report of Ability of Countries to Disaggregate SDG Indicators by Disability, 2016, https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/WG_Implementation_Document_10_-_SDG.pdf (10.11.2020).

76 Ibid.

77 Washington Group, WG Conceptual Framework, 2016, <http://www.washingtongroup-disability.com/methodology-and-research/conceptual-framework> (10.6.2020).

78 Daniel Mont, Why Global Health And Functioning Indicators Like The GALI Are Not Suitable for Disaggregation, 2019, <https://www.washingtongroup-disability.com/wg-blog/why-global-health-and-functioning-indicators-like-the-gali-are-not-suitable-for-disaggregation-98/> (10.11.2020).

a social model approach to disability;⁷⁹ the level of functioning (impairment) provides the base for assessing the equalisation of opportunity (relation between impairment and environment).⁸⁰ Before the WGQ were introduced, “there were two main ways data on disability were collected. Either respondents were asked if they had a disability or they were asked if they had one of a list of medical conditions”.⁸¹ In 2018, ten governments committed themselves to use these questions in upcoming national censuses or surveys (Kenya, Kyrgyz Republic, Malawi, Mozambique, Nigeria, Rwanda, Sierra Leone, Tanzania, Uganda, and Zambia).⁸²

*Washington Group Short Set on Questions of Disability*⁸³

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

For each question, the response options are:

- a. No – no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

How do these questions depict the relation between impairment and environment? And how do they contribute to determine how inclusive education systems have

79 Daniel Mont, How are the Washington Group Questions consistent with the Social Model of Disability?, 2019, <https://www.washingtongroup-disability.com/wg-blog/how-are-the-washington-group-questions-consistent-with-the-social-model-of-disability-65/> (10.11.2020).

80 Washington Group, Washington Group Position Paper: Proposed Purpose of an Internationally Comparable General Disability Measure, 2004, 3–4, https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Events/3/3.6_purpose_paper.pdf (10.11.2020).

81 Mont, Disaggregating, 2019, 12.

82 United Kingdom Department for International Development [UK DFID], Global Disability Summit: One Year On – Accountability Report, 2019, <https://www.gov.uk/government/publications/global-disability-summit-one-year-on-accountability-report-2019/global-disability-summit-one-year-on-accountability-report-2019> (10.6.2020).

83 Washington Group, The Washington Group Short Set of Questions on Disability, n.d., <http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/The-Washington-Group-Short-Set-of-Questions-on-Disability.pdf> (10.6.2020).

become for persons with disabilities? To answer this question, we will reconstruct the symbolic order of disability entailed in the Short Set of Questions. For this purpose, we will first outline their discursive frame, secondly reconstruct their disability classifications and finally discuss the entailed relation between impairment and environment.

Discursive Framework: International Classification of Functioning

At a conceptual level, the WGQ are based on the International Classification of Functioning, Disability and Health (ICF), introduced by the WHO in 2001.⁸⁴ The ICF presents a disability classification system that encompasses functioning – at the level of body structures, activities and participation – as well as context – regarding personal and environmental factors. In this way, the ICF incorporates a bio-psycho-social model of disability based on the fundamental idea that the “various types of functioning” are “influenced by environmental barriers, be they at the micro-, meso-, or macro-level”.⁸⁵

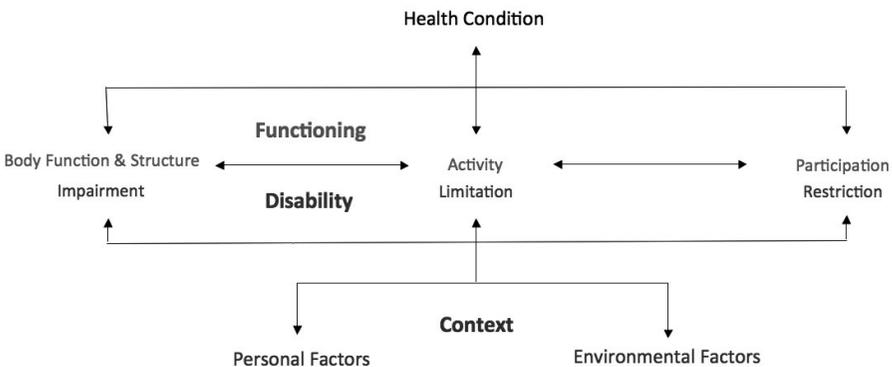


Figure: International Classification of Functioning, Disability and Health (ICF)⁸⁶

Within this classification system, disability serves as “an umbrella term for impairments, activity limitations or participation restrictions”.⁸⁷ Impairments are defined

84 See WHO, International Classification of Functioning, Disability and Health (ICF), Geneva 2001, <https://apps.who.int/iris/bitstream/handle/10665/42407/9241545429.pdf;jsessionid=725A1D5F4247CB437DF216C5D5390174?sequence=1> (10.6.2020); Washington Group, WG Conceptual Framework, 2016; Mont, Washington Group Questions, 2019.

85 Mont, Washington Group Questions, 2017.

86 Based on WHO, International Classification, 2001, 11.

87 Ibid., 3.

as “problems in body functions or structures”, activity limitations as “difficulties an individual may have in executing activities” and participation restrictions as “problems an individual may experience in involvement in life situations”.⁸⁸ Functioning and disability are thus complementary terms, indicating either negative or positive aspects of the interaction between an individual’s health condition and contextual factors.⁸⁹ The distinction between disability and functioning on the one hand, and contextual factors on the other hand serves a social model approach to disability. It highlights the relevance of environmental barriers for the limitation of activities and the restriction of participation. Taking up the distinction between functioning, disability and context, the WGQ aim to collect data on disability as a social rather than a medical phenomenon. But who is then classified as a person with disability, and how is the relation between a person and their environment actually conceptualised?

Disability Classification: The Relation Between Impairment and Activity Limitations

The WGQ assess how people from the age of five experience difficulties in core functional domains of seeing, hearing, walking, cognition, self-care and communication. There are four ways to respond: ‘no difficulty’, ‘some difficulty’, ‘a lot of difficulty’ or ‘cannot do at all’. People are identified as disabled if they have at least ‘a lot of difficulty’ in at least one of the six areas.⁹⁰ The focus is on health problems, with health referring “to the general condition of the body or mind” and problems referring “to the respondent’s perception of a departure from physical, mental or emotional well-being”.⁹¹ By referencing body functions and structures, the diagnostic categories of impairment seem to be replicated: blindness, deafness, mobility impairment, cognitive impairment as well as psychosocial wellbeing and communication. For that reason, it seems as if the WGQ prioritise bodily functions over their relation to activity and participation, suggesting an equation of impairment and disability.

However, an alternative conclusion can be drawn when we focus on the phrasing of the questions, in particular the expression ‘difficulties, even if’. In asking about difficulties which persist even if technical devices such as glasses or hearing aids are used,

88 Ibid., 10.

89 Ibid., 11.

90 Mont, *Disaggregating*, 2019, 12.

91 Washington Group, *The Washington Group Short Set on Functioning: Question Specifications*, 2017, 2, <https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Events/17/WG-Document-4-The-Washington-Group-Short-Set-on-Functioning-Question-Specifications.pdf> (5.11.2020).

both the interviewees' impairment as well as the availability of assistive equipment are addressed. Only if persons with impairments encounter difficulties that cannot be compensated with technical aids or assistive devices, they are classified as disabled. Conversely, persons who do not encounter difficulties – either because they have no impairment or because aids compensate related difficulties – are not classified as disabled. The symbolic border between persons with and without disabilities is therefore not drawn based on an impairment; instead, it is drawn within the group of persons with impairments by distinguishing between those who do, or do not, encounter activity limitations because of limited assistive devices. For this distinction to be made, the underlying assumption is that impairments can be compensated so that activity limitations can be overcome. Disability, in turn, is assumed when a person with impairments encounters problems in the performance of activities that cannot be compensated with basic technical aids.

Therefore, impairment and disability are not the same; while the classification of disability is based on the assessment of impairment, it is not limited to it. The WGQ go further than simply stating that disability is nothing else than a medical condition of impairment. They, in addition, provide information on the availability and effectiveness of assistive devices to overcome “difficulties an individual may have in executing activities”.⁹² In so doing, the WGQ allow to model disability as an interaction between impairment and the provision of aids – as one specific environmental factor. The idea that disability results from a relation between person and environment is therefore inherent in the WGQ, albeit only to a limited extent.

Disability Data: The Relation between Activity Limitations and Participation Restrictions

Indeed, the Washington Group is aware of this limitation. Responding to the critique that the question-set “represents the medical model because it does not ask about participation or environmental barriers”, the Washington Group explains: “it is true that the specific questions in the WG SS do not directly address participation and environment”; rather, they “obtain information on one aspect of the ICF (basic activity limitations)”.⁹³ The separation of body function and activity from participation is based on the idea that function-based activity restrictions affect participation. This idea, however, is not explicitly conceptualised. Even more, the Washington Group rejects a participation definition of disability, as it would “not allow us to

92 WHO, International Classification, 2001, 10.

93 Mont, Washington Group Questions, 2019.

compare the outcomes for people with and without disability”.⁹⁴ They instead propose to establish the actual degree of participation in data analysis rather than in the process of data collection, for example when levels of access to education or completion rates are compared.⁹⁵ “The WG questions focus solely on difficulties in core functional domains to create a disability identifier, and by cross classifying this variable with outcome measures (like employment), we are able to see that people at risk of non-participation are now participating”.⁹⁶ In this context, inclusion and exclusion emerge as complementary terms. Inclusion is assumed when no exclusion takes place; that is, when activity restrictions are either not present or compensated, thus reducing the risk of non-participation. In turn, exclusion is assumed when activity restrictions reduce the possibility for participation so that persons become disabled on the ground of their impairments.

There are, however, two problems with this approach: first, we do not know why people with disabilities can or cannot access and participate in education, that is, whether or not the compensation of the impairment is sufficient. Secondly, we do not know whether people with impairments whose activity restrictions are compensated by technical aids face exclusions and, if so, which ones. Indeed, impaired persons can still face a *risk of non-participation*, for example when schools are unavailable or inaccessible. Therefore, the proposed relation between activity restrictions and (limited) participation remains under-complex, especially as this relation is always culturally and environmentally determined and thus context-dependent. For example, a comparative study between Nigeria and Germany revealed that the contrasting capacities of schools to provide special education (or not) have a huge influence on the understanding of how, where and when children with disabilities can and should participate.⁹⁷

In terms of SDG4-monitoring, therefore, the crucial question is not just whether or not people with disabilities participate in education. In addition, the social model approach to disability requires to address the organisational, structural and/or cultural barriers that impact the availability and accessibility of education for all; for example, barriers a person faces in accessing educational institutions or barriers inherent in educational institutions. By not addressing these barriers, social processes of disablement fade into the background, contrary to what the human rights norm of inclusion would require. These ambivalences demand to reflect how the interaction between people and their environments is conceptualised in and for human rights monitoring by actors at different levels. From a Disability Studies

94 Mont, Global Health, 2019.

95 Mont, Washington Group Questions, 2019.

96 Mont, Global Health, 2019.

97 Biermann, Sonderpädagogisierung, 2019.

point of view, this reflection implies to understand that a social model approach to disability is not already fulfilled by collecting data based on the WGQ. While the questions allow to identify persons with disabilities in order to subsequently compare their educational outcomes with those of their non-disabled peers, they do not allow to determine the level of inclusivity of education systems. Therefore, the assessments of countries' progress in achieving SDG4 would instead require to complement standardised quantitative education data with contextual, qualitative data on the social and institutional factors that affect participation and equal opportunity for persons with disabilities in education. Only this combination would allow depicting the scope of context-specific disability experiences, which, in turn, would provide an accurate basis to determine the extent to which education systems become more inclusive.

Summary and Conclusion: A Social Model of Impairment in Human Rights Monitoring for Inclusive Education

This article has highlighted the importance of comparable, disability-disaggregated data for the institutionalisation of a global assessment practice. We have shown how a social model approach to disability was incorporated into the realm of human rights and how it is currently applied in assessing countries' progress in realising the right to inclusive education for persons with disabilities.

In the historical analysis we identified three phases during which the rights of persons with disabilities were incorporated into the human rights canon. An absolute silence on the rights of persons with disabilities to education characterised the early human rights discourse between the 1940s and 1960s, reflecting a medical approach to disability. The discourse between the 1970s and 1990s shifted the focus on persons with disabilities as a group deprived of their rights globally, coining a social model approach based on a relational understanding of person and environment. Starting in the 2000s, the international discourse eventually anchored the human rights of people with disability with passage of the UN CRPD. The social model approach to disability thus codified was then incorporated into the SDGs, the most recent global development agenda.

To measure progress in implementing the Sustainable Development Goals (SDGs), the UN monitoring mechanism requires disability-disaggregated data to be produced by national actors with the help of the Washington Group Questions (WGQ). In the second analysis, we examined how the WGQ apply a social model approach to disability by reconstructing the relation they propose between impairment and environment. This reconstruction revealed that the WGQ allow identifying

persons with impairments who are not adequately supplied with aids and therefore face activity restrictions. Activity restrictions are seen as putting them at risk of non-participation – the ultimate indicator for inclusion or exclusion. Measuring disability in this way, the WGQ advance a relational approach to disability in data collection for the assessment of inclusion. They highlight the role of social environments for participation but restrict them to assistive devices. Therefore, we conclude that the WGQ advance a social model of impairment instead of a social model of disability. In this way, the WGQ hint at, yet do not fully capture the complex relation between participation restrictions and contextual factors. The result is ambivalent: a social model approach to disability is enforced in a human rights context by omitting its unique feature – disability is not measured as a relation between impairment and context, but as an activity limitation due to an impairment *and* a lack of assistive devices. In this way, the need for disability-disaggregated education data is satisfied, but not for monitoring practices that fulfil the requirements of a social model approach to disability.

Overall, the analysis has shown the twofold challenge of institutionalising a global human rights monitoring practice, which involves experts and organisations both at a national and international level: first, the requirement to firmly establish a global norm based on which assessments can be made; in our case, this was the formalisation of inclusive education as a human right for persons with disabilities. Secondly, the necessity to develop a robust, globally comparable measurement tool that allows to apply the established human rights norm in assessments of countries' progress; in our case, these were the WGQ promoted by the UN to identify persons with disabilities in order to track their access and participation in education.

Having reconstructed historical and current UN disability knowledge, we have concluded that the global monitoring of human rights based on a relational model of disability foregrounding the interaction between impairment and environment is an assessment practice in the making; it supports the goal of making the lives of persons with disability better, but has not yet achieved its full potential. The latter would require that actors in administration, politics and science increasingly reflect on the ambivalences of disability measurements in a global context, in particular the power-related and methodological problems of approaching disability as an impairment not compensated by assistive devices or technical aids. This could be done by explicitly dealing with the institutional processes of exclusion and inclusion in education at and across national levels. To this end, experts generating data for human rights monitoring and examining countries' progress in realising SDG 4 would need to further broaden their understanding of disability as a social phenomenon, and to assess the meaningfulness of disability data accordingly. Eventually, the international

community will need to develop more robust procedures for the production of inclusive data that allow to capture the barriers impeding the realisation of human rights for persons with disabilities more comprehensively.