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# Developing disability equality indicators: national and transnational technologies of governance

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## ABSTRACT

The paper assesses the development of disability equality outcome indicators in 35 European countries in a context of the global governance of human rights and development. Outcome indicators are well-known in other fields, notably in the field of gender equality, but have been much less evident in the disability field. This is, in part, due to difficulties of disability definition and measurement but also reflects the relatively recent formalisation of disability equality as a global human rights concern. Over the past decade there has been a rising expectation on states to structure and quantify their monitoring of disability equality and rights. Despite this there is only patchy evidence that transnational governance frameworks have had any great effect on states' compliance with this. The first part of the paper reviews the meaning of disability equality and the duty on states to monitor it. The second part assesses the progress made in European countries, including examples of variations in approach and coverage. Acts of equality measurement make injustices more visible and more governable. In this sense public investment in disability equality indicators is still much needed.

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Disability; equality; social indicators; human rights monitoring; global governance

This paper examines public efforts to quantify equality of outcomes for disabled people when monitoring the progressive realisation of their rights to social inclusion at the national level. Outcome indicators are well-known in other fields, notably in the field of gender equality, but how transferable are they to the field of disability equality? What progress has been made and what remains to be done? The paper considers, systematically and for the first time, the evidence from European countries in relation to the expectations of global rights governance. The first part of the paper reviews the meaning of disability equality and the duty on states to quantify it. The second part assesses the progress made in 35 European countries.

## The idea of equality and its measurement in governing disability rights

It is not possible here to review all the meanings of equality, suffice to say that the concept has been framed largely by theories of justice. We can think of equality in terms of

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negative rights (freedom of self-determination) or positive rights (access to resources) but there is tension between these.<sup>1</sup> Recognising that ‘freedom’ alone often leads to inequalities, Rawls justified public intervention on grounds of ‘fairness’ as one of the co-foundations of liberal society.<sup>2</sup> For Rawls, equality went beyond civil or political freedoms to include the fair distribution of resources based on equality of opportunity and greatest benefit for those most disadvantaged. Such ideas have informed the way we think about fairness in European welfare states. Understanding equality to include the distribution of resources, and social participation, opens the possibility to measure outcomes in these terms.

Posing the question ‘Equality of what?’, Sen surveyed the limitations of existing equality models and proposed the idea of ‘basic capability equality’.<sup>3</sup> One concern for Sen was that measures of equal resource distribution may overlook the relations between available resources and the capabilities of individuals to put them to use. For example, an objective measure of ‘equal’ incomes might overlook the higher costs of living faced by many disabled people (who might need *more* rather than equally distributed resources to achieve the same social ends as others). This argument is closely related to the rationale for ensuring reasonable accommodation (or adjustment) in ensuring non-discrimination and equality of opportunity.<sup>4,5</sup> These and other general conceptualisations of social justice have strengthened the justification for greater public attention to disability equality but say little, explicitly, about how to measure its outcomes.<sup>6,7</sup>

Disability is a complex, multidimensional phenomenon. Its definition and measurement are contested and can be difficult to operationalise in public statistics.<sup>8</sup> Disablement is a process that impacts people lives cumulatively and across many dimensions – in employment, housing, educational attainment, income and wealth generation, health, isolation, and so on. It also interacts with, and compounds, other dimensions of exclusion (such as gender, ‘race’ or age inequality). Disability must be considered both as a distinctive dimension of human rights and as a cross-cutting dimension in any general system of equality measurement.

The idea of disability equality is underpinned by the historic claims of disabled people’s movements to ‘full participation and equality’, based upon:

The right of every disabled person to share in the social life of the community in which he or she lives and enjoy living conditions *equal to those of other citizens*, including *an equal share* in the improvement in standard of living resulting from social and economic development. [emphasis added]<sup>9</sup>

Similar aspiration has been embedded in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) for more than a decade. CRPD requires that disabled persons should be able to participate in society ‘on an equal basis with others’ and that states should evidence their progress towards this. When monitoring its implementation, measuring participation outcomes for rights holders is one way to make inequalities more visible and thereby more governable.<sup>8</sup> The CRPD Committee has further elaborated a concept of ‘inclusive equality’ in a General Comment, and underlines the obligation on states to promote equality of outcomes as well as equality of opportunity.<sup>10</sup> In particular, the interpretation calls on states to:

Adopt appropriate measures to monitor inclusive equality regularly and comprehensively. This includes collecting and analysing disaggregated data on the situation of persons with disabilities;

As we have outlined previously in this journal, the Office of the UN High Commissioner for Human Rights (OHCHR) elaborated a threefold typology of indicators to take account of ‘structure’, ‘process’ and ‘outcome’,<sup>11,12,13,14</sup> corresponding broadly to Landman’s distinction between measures of human rights in principle, policy and practice.<sup>15</sup> This paper focuses on the dimension of outcome measures.

The ingress of indicators into international human rights governance began with more qualitative, criterion-based indicators, such as evidence of transposing an international policy instrument into the ‘structure’ of domestic law.<sup>16</sup> The development of ‘Process’ indicators focused more on the efforts that states make to implement such laws, including the significance of reasonable accommodation in this process, while ‘Outcome’ indicators seek to capture consequent attainments for rights holders.<sup>17</sup> Initially, more effort was invested in evidencing respect for human rights in principle than their realisation by rights holders in practice.<sup>15</sup> For this reason, we focus on the latter category, specifically state efforts to quantify equality of participation outcomes between disabled persons and other persons.

Measurement is not new to the field of human rights<sup>18,19,20,21</sup> and ‘The concept of equality, which pervades internationally defined human rights standards, implies comparison and measurement’.<sup>22</sup> Indeed, Rosga and Satterthwaite cited the OHCHR as one example of developing ‘trust in numbers’,<sup>23</sup> observing that:

The explosive demand for “indicators” that can be used to determine the degree to which States are living up to their human rights obligations is intimately connected with the trust in data that is understood to be abstract, quantifiable, and putatively transferable.<sup>24</sup>

There have been some concerns that such quantification changes ‘the topology of global governance’<sup>25</sup> by introducing ‘calculative technologies’ for ‘governing at a distance’.<sup>26</sup> international standardisation of equality measurement would strengthen the idea that, ‘it is the interface between globalisation and human rights that challenges state autonomy most forcefully ...’.<sup>27</sup> Some rights defenders may view statistical indicators as tempting a new managerial culture of governance ‘at a distance’ yet such indicators also have great potential to reveal evidence about inequalities and rights abuses. Equality indicators can help to hold states to account for their policies, transparently, provided their conceptualisation is clearly articulated and their measurement sufficient for purpose.<sup>28,29,30,31</sup> In addition, the effort states invest in measuring inequality is already a symbolic indicator of its public recognition.

The growth of social indicators as technologies of global governance is evident across many policy fields and increasingly deploys statistical means (e.g. in the recent integration of 169 targets in the Sustainable Development Goals framework for monitoring of the UN Agenda 2030).<sup>32</sup> Before examining how states are developing quantified outcome measures in the field of disability rights it is useful to understand more about the expectations upon them to do so.

## The duties on states to produce data on disability equality

The policy drivers for development of national disability equality indicators have arisen from both international and domestic governance. For example, at the global level, both the CRPD and the SDGs anticipate that states will develop comparative indicators of social participation.<sup>33</sup> The CRPD is underpinned by a goal of ‘full and effective participation in society *on an equal basis with others*’ (emphasis added). This suggests that the key challenge is a relational one – how to measure the ‘participation’ of disabled persons in relation to ‘others’. Disabled people should be able to fully exercise their universal human rights ‘on an equal basis with others’, and for children ‘on an equal basis with other children’ (Article 7). This formulation of equality is repeated more than 30 times in the text. A similar meaning is conveyed by ‘equal opportunity’ (one of eight guiding principles that animate the Convention) as well as various references to ‘equal recognition’, ‘equal protection’, ‘equal rights’, ‘equal access’ or ‘equal participation’.

For example, Article 9 on Accessibility requires, ‘access, on an equal basis with others, to the physical environment, to transportation, to information and communications’. Article 24 on Education includes commitment to ensure that ‘Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live’. Article 27 on Work and Employment includes assurances of ‘equal opportunities and equal remuneration for work of equal value’, and so on. The development of outcome indicators ought to reflect such obligations in order to monitor evidence of their progressive realisation by rights holders (alongside the evidence of legal structure and policy process).

In its methodological guide, the UN distinguishes human rights outcome indicators from general statistics in that their primary purpose is ‘to measure the enjoyment of rights by rights holders’.<sup>13</sup> This means they should be anchored in the normative content of international human rights standards and reveal outcomes for the protected group in question. UN guidance for disability human rights monitors affirms that states are obliged to develop a plan of action with benchmarks and indicators of success and that these should be identified when states report on their CRPD implementation.<sup>34</sup>

Under Article 31(1) CRPD, ‘States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention’. The reporting guidance envisaged that state reports to the UN should include:

Statistical data on the realization of each Convention right, disaggregated by sex, age, type of disability (physical, sensory, intellectual and mental), ethnic origin, urban/rural population and other relevant categories, on an annual comparative basis over the past four years;<sup>35</sup>

This has proved very challenging in practice but there are examples of promising practice (as we show later). Nevertheless, it is clear that statistical outcome indicators ought to be a key component of any system of ‘concurrent multinational monitoring’, from which they remain notably absent in the disability field.<sup>36</sup> In addition, Article 31(3) requires states to ‘assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others’. This is an important consideration in holding states accountable for equality measurement.

To summarise, equality is a key principle of the CRPD. States should develop statistical outcome measures as one part of their monitoring obligations. Such indicators should include comparisons between the participation of disabled persons and other persons in society. They should be disseminated publicly and be easily understood.

In parallel with CRPD, the UN 2030 Agenda for Sustainable Development has manifested new global indicators for monitoring progress towards the SDGs. Several of the supporting targets mention disability and others should be disaggregated, where possible. With this in mind, an SDG Advocacy Toolkit for disability indicators was developed in 2015 by the UN, the International Disability Alliance (IDA) and the International Disability and Development Consortium (IDDC).<sup>37</sup> There have been numerous calls to strengthen the methodology and standards for inclusion of disability statistics since then.<sup>38</sup> Yet, in 2020, the SDG indicator database disposed only three measures disaggregated with disability data and even these remained incomplete (these relate to disability cash benefits, the accessibility of schools, and unemployment).<sup>39</sup> The SDG indicators provide an important symbolic commitment to measure disability equality but they also reveal the difficulty in realising this in a systematic way.<sup>33</sup>

The UN's Disability Statistics Programme has produced a great deal of work to facilitate exchange among, and guidance to, national statistical authorities but this has focused more on harmonisation of data collection than on the selection of indicators. Its initial *Guidelines and Principles for the Development of Disability Statistics* were drafted prior to the CRPD but did envisage the need for comparative participation data to 'monitor equality of opportunity and achievements made, in terms of economic, social, political and cultural rights'<sup>40</sup> and 'to assess the extent to which there is equality of opportunity as stated in various international policy documents'.<sup>40</sup> An expert meeting was held in 2017 to revise these Guidelines in response to the CRPD and SDGs but a new edition has not been published yet.

At the European level, interest in the development of disability equality indicators predates these global frameworks but has not, so far, been very formalised by EU institutions. Eurostat has published a number of disability tables in its 'Health' database, which include various outcome measures.<sup>41</sup> The European Commission sponsored the development of indicator proposals compatible with EU disability strategy and the CRPD in 2009, prior to its ratification<sup>42,43,44</sup> and have utilised such examples to evidence inequalities.<sup>8</sup> There is no explicit duty on EU Member States to produce disability equality indicators but in the latest iteration of EU disability strategy the European Commission commits to:

develop, at the latest by 2023, new disability indicators with a clear roadmap for implementation. These should include indicators for children and the situation of persons with disabilities in employment, education, social protection, poverty and social exclusion, living conditions, health, use of new communication technologies, supporting the indicators for the EU Social Scoreboard, the European Semester [and] Sustainable Development Goals;<sup>45</sup>

As shown so far, disability is a latecomer to the field but measuring equality is not a new challenge for states. There have been numerous attempts, over decades, to develop indicators and indices of equality, notably in the fields of gender equality and race equality and especially in Europe. In the remainder of this paper, we examine the progress of European states in developing quantitative indicators of disability equality.

## Method

The research in 2019 included 35 countries – the then Member States of the EU and its candidate or associated countries. We used global and European databases to systematically identify examples of national indicator initiatives – namely, the treaty database of the UN Office of the High Commissioner for Human Rights and the Disability Online Tool of the Commission (DOTCOM), developed by the Academic Network of European Disability experts (ANED).

The UN database provides an archive of all reporting and dialogue between states parties, the CRPD Committee and civil society. Considering the expectation that states should evidence data and statistics, we first examined the initial reports from those that had reported (31 countries). We then examined the Committee's Concluding Observations for those having completed at least one cycle of dialogue by June 2020. The purpose was to identify where the Committee had highlighted indicator development as an achievement, a concern or a recommendation for action. In both document sets we examined the texts relating to Article 31 CRPD and then searched the remainder of the documents for relevant terms.

The DOTCOM database provides a repository of information about national disability laws and policies of countries associated with the EU/EEA. It was designed by the first author of this paper for the Disability and Social Inclusion Unit of the European Commission Directorate General for Employment and Social Affairs and populated by national experts in 35 countries.<sup>46</sup> The database covers eight policy, including one on 'Statistics and data collection'. This covers national developments in, 'Official research' (Theme G.1), 'Census data' (Theme G.2), 'Labour Force Survey' (Theme G.3), and 'Disability equality indicators' (Theme G.4). Each has some relevance but our main focus is on the latter item.

Each record included a brief descriptive summary with links to policy documents or national sources of further information. This content was populated in 2012 and updated annually to 2019 and country experts were invited to 'identify whether there is any set of disability equality indicators based on public data sources' and to 'summarise what is included and which agency or office is responsible'. The most recent data was generated between December 2018 and May 2019, and retrieved from the database in November 2019.<sup>47</sup> Additional reference to indicators were identified in ANED country reports providing a disability perspective on the European Semester, which included information about 'national disability strategies, plans and targets' relevant to employment, education and poverty or social exclusion.

We reviewed these datasets to identify policy examples and source documents for further analysis of each national case. This following analysis focuses on examples of purposeful, rather than incidental, efforts to quantify disability equality indicators at the national level, and their relationship to frameworks of transnational governance.

## Global governance and national indicators

All of the initial state reports submitted to the UN CRPD Committee made some reference to data collection or statistics, as required under Article 31, but there were few explicit references to indicator development. A minority referred to the existence of one or



more indicators but very few mentioned any purposeful or systematic development. Only three reports suggested a nationally co-ordinated effort.

Hungary reported that, on government request, a civil society foundation had:

... compiled an indicator list highlighting the implementation of international documentations on disability matters; the purpose was to set up an indicator list to control and assist the implementation of the Convention on the Rights of People with Disabilities, the ten-year action plan of the Council of Europe and the disability action plan of the European Union.<sup>48</sup>

This example was used to inform civil society shadow reporting, rather than state monitoring obligations, but it illustrated some purposeful interaction between national indicator development and international governance frameworks. Germany referred to criticism from civil society that ‘indicator-supported evaluation policy on persons with disabilities was lacking so far’. Consequently, its national disability reporting cycle had been redesigned in 2012, ‘to initiate the implementation and gradual introduction of a new indicator-based disability reporting on this basis’, including to ‘Ensure comparability through indicators with a fixed definition’.<sup>49</sup> Finally, Turkey identified a specific project to support CRPD monitoring, initiated with UN support in 2013. The aims of this project included ‘reviewing the rights of PwDs within the frame of human rights and developing indicator sets for monitoring these rights’.<sup>50</sup>

The 31 state reports spanned more than a decade of implementation (2008–2019) but the very sporadic attention they gave to co-ordinated indicator development suggests that this concept remained rather marginal to national discourse on rights governance throughout the period. This contrasts with the expectation of the UN Committee charged with monitoring them, who invoked the language of comparable data and indicators much more frequently.

Sometimes the Committee recommended rights-based indicators for specific CRPD Articles, as in Lithuania or Italy in 2016.<sup>51,52</sup> It was concerned, more generally, about a lack of ‘human rights indicators’ in Portugal, recommending that it ‘use a human rights-based indicators system’.<sup>53</sup> Often the same words of general recommendation were repeated to different countries, such as to Spain (2011), Hungary (2012), Austria (2013), Belgium (2014) or Portugal (2016), urging them all to:

... develop gender-sensitive indicators to support legislative developments, policymaking and institutional strengthening for monitoring, and report on progress made with regard to the implementation of the various provisions of the Convention.

The governance expectation is that indicators should help to align national policy monitoring with international policy norms. For example, the recommendation to Slovakia was to co-ordinate the development of (national) ‘policy, action plan and indicators’,<sup>54</sup> while the advice to Denmark called for stronger links between national objectives, ‘measurable targets, adequate budget, and indicators, to evaluate progress in the implementation of the Government’s disability policy’ and CRPD.<sup>55</sup> The advice to Sweden went further, expressing concern that:

... the system of indicators established by the State party to monitor the implementation of the Convention is based only on those areas that strictly relate to the disability policy and does not cover broadly all of the rights areas under the Convention, and that there is a lack of indicators.<sup>56</sup>



So far, the UN Committee has not elaborated a General Comment on Article 31 CRPD, clarifying its expectations on statistics and data collection. The preceding analysis suggests that it took seriously the duty on states to collect data and envisaged that national disability indicators would provide a means to align national policy with the international human rights governance framework. The initial reports from states suggested that very few European states had done so.

### **Policy drivers for indicator development in European countries**

Moving to national sources, beyond the CRPD governance process, we identified examples of disability equality indicators in at least 22 out of the 35 countries. These can be divided into those that were aligned to transnational policy frameworks or to national disability strategy, and those that appeared incidental to policy development.

Several examples were aligned explicitly towards the CRPD or the SDGs. The Danish Institute for Human Rights developed a set of ‘Gold Indicators’, covering ten Articles of the CRPD, and a ‘disability barometer’ tool based on this.<sup>57,58</sup> Monitoring of the Austrian *National Action Plan on Disability 2012–2020*, framed by the CRPD, included several quantifiable measures of policy implementation but these were mainly process rather than outcome oriented.<sup>59</sup> Data and indicator development initiatives were also integral to Croatian disability strategy, which in turn was closely aligned to the CRPD.<sup>60</sup> In Germany, statutory reporting on the situation of disabled people had been realigned towards the CRPD. The Danish and German examples are considered as case studies later.

Preparations for a Turkish national disability strategy established a comprehensive (87 page) document on *National Indicators for the Rights of Persons with Disabilities* under the UN Convention, following the UNOHCHR typology of structure-process-outcome indicators.<sup>61</sup> In Spain, the State Disability Observatory (OED) used an indicator-based approach to report under its remit to promote policies in accordance with the CRPD.<sup>62</sup> In the United Kingdom, the Office for Disability Issues (ODI) published a set of 48 ‘Disability Equality Indicators’ on its website, linked to a previous national disability strategy and the UN Convention, prior to its ratification in 2009 although these were not maintained.<sup>63</sup> The Spanish and UK examples are elaborated later.

It was much less common for national indicators to be aligned explicitly with European level strategy, such as the European Disability Strategy 2010–2020. In Greece, a National Disability Observatory, developed some disability indicators aligned with the framework of the EU2020 strategy, concerning its goals on employment, education and risk of poverty or social exclusion. This was similar to the approach taken in ANED’s indicators of disability equality in Europe and their disaggregation of national participation data was strongly influenced by EU benchmarks and surveys.<sup>64,65</sup> The Croatian national strategy was explicitly linked to the Council of Europe disability strategy, as well as CRPD, but this was not clearly reflected in the choice of indicators.

In most cases disability equality indicators were more aligned with national priorities than with international frameworks like the CRPD, hinting at a rather limited impact of global governance. In Ireland, the National Disability Authority (NDA) developed indicators to monitor outcomes for disabled persons against five strategy goals using a national disability survey.<sup>66</sup> In France there was little recent evidence of co-ordinated indicator development since the Ministry of Labour, Employment and Health published

indicators on disability employment and unemployment a decade previously.<sup>67</sup> In Slovakia, the National Disability Programme for 2014–2020 (measure 4.17.1) envisaged the development of ‘Selected indicators related to the social situation of persons with disabilities’ but these had not yet been implemented beyond employment statistics.<sup>68</sup> In Cyprus, future rights-based indicator development was also anticipated on the basis of a new system of disability assessment.<sup>69</sup>

Further examples were relevant to national disability strategy incidentally but not clearly aligned with it. For example, in the Greek example, above, there was no co-ordinated disability strategy but the law required public bodies to maintain disability statistics in their areas of responsibility and ‘to take account of the rights of persons with disabilities, as described in the Convention’ (§68, law 4488/2017). In Estonia, the statistical office published a special bulletin on the *Social Integration of Disabled Persons* in 2014.<sup>70</sup> In Malta, a report on *The Quality of Life of Disabled People* was published, based on disaggregation of 2005 Census data.<sup>71</sup> The Swedish Agency for Participation (MFD) published some equality indicators, notably in annex to its annual thematic reports.<sup>72</sup> In Iceland, a small number of disability measures were disaggregated in national social indicators.<sup>73</sup> In the United Kingdom, indicators of labour market status were reported quarterly from the Labour Force Survey.<sup>74</sup>

There were also examples of indicator development by non-state actors. For example, in the Flanders region of Belgium a civil society association developed and published an evidenced based ‘Inclusion Mirror’ report.<sup>75</sup> In Portugal, the academic Disability and Human Rights Observatory (ODDH) published ‘human rights indicators’ reports based on national and international disability data.<sup>76,77</sup> In the Netherlands, the Institute for Human Rights facilitated national indicator development on independent living, education and employment, in collaboration with civil society, researchers and the Central Bureau of Statistics.<sup>78,79</sup> Such examples were utilised in civil society shadow reporting to the CRPD monitoring process, rather than by state actors.

In 2019, no clear evidence of nationally co-ordinated disability equality indicator development could be identified from the data in the EU Member States of Bulgaria, Croatia, Czech Republic, Finland, Hungary, Italy, Latvia, Lithuania, Luxembourg, Poland, Romania, Slovakia or Slovenia. Similarly, no evidence was found concerning indicator development among the non-EU states of North Macedonia, Iceland, Montenegro, Serbia or Liechtenstein.

As this initial review suggests, in the field of disability equality, the value attached to rights-based indicators in global governance frameworks has not been not matched by the effort invested in developing them as tools of national governance. There has been a clear expectation at the global level for at least a decade that states should invest in more systematic approaches, including indicators aligned with a rights-based strategy. There is only patchy evidence that this has happened in a purposeful or co-ordinated way among European states. Nevertheless, some of the examples merit further exploration.

## Approaches to national indicator development

The following five examples, identified from the preceding reviews, illustrate differences of approach, coverage and dissemination in the development of national disability equality indicators. In each case there was evidence of a purposeful and co-ordinated effort to

produce a defined set of quantitative outcome measures, linking national priorities and the framework of global rights governance in some way. These included initiatives led by governmental and non-governmental (or quasi-governmental) actors. All are based on a much smaller number of selected themes (3–10) than the number of CRPD Articles, but often cross-referencing them, then sub-divided to a larger number of specific measures (between 30 and 50 items). An indicative overview of their thematic relevance to CRPD Articles is provided in [Table 1](#).

### **Dutch insights into inclusion**

In the Netherlands, the national human rights institute (*College voor de Rechten van de Mens*) led the initiative to develop national disability equality indicators. This was prompted explicitly by its mandate to monitor national implementation of the CRPD. In collaboration with its civil society stakeholders, the College commissioned the national statistical office and a national research institute to produce statistics.

Three specific CRPD Articles were chosen and covered by 37 indicators, populated from national social survey data every four years. Reports of around 50 pages are published on the institute's website, with a factsheet summary. The aim was 'to gain insight into the extent to which people with a disability can participate in the society' and to provide a 'thermometer' of human rights standards.<sup>80,81</sup>

### **The Danish disability index**

In Denmark too, indicator development was led by the national human rights institution (the Danish Institute for Human Rights) and closely aligned towards the CRPD, with

**Table 1.** Relevance of indicators to CRPD articles.

CRPD Articles	De	Dk	Nl	Uk	Es
5: equality and non-discrimination		X			X
6: women with disabilities					X
7: children with disabilities				X	
8: awareness-raising		X		X	
9: accessibility		X		X	
10: right to life					
11: situations of risk and humanitarian emergencies					
12: equal recognition before the law		X		X	
13: access to justice				X	
14: liberty and security of person					
15: freedom of torture or cruel, inhuman or degrading treatment or punishment					
16: freedom from exploitation, violence and abuse	X	X		X	X
17: protecting the integrity of the person					
18: liberty of movement and nationality					
<b>19: living independently and being included in the community</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
20: personal mobility					
21: freedom of expression and opinion, and access to information				X	
22: respect for privacy		X			
23: respect for home and the family	X	X		X	
<b>24: education</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
25: health	X	X		X	X
26: habilitation and rehabilitation				X	
<b>27: work and employment</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
28: adequate standard of living and social protection				X	X
29: participation in political and public life	X				X
30: participation in cultural life, recreation, leisure and sport	X				X

connections also to the SDGs. According to the developers, the initial ‘Gold Indicators’ were ‘inspired by’ the UK’s Equality Measurement Framework and by ANED’s work on Indicators of Disability Equality in Europe.<sup>58</sup> They referred also to UN ESCAP’s disability indicators supporting the Incheon Strategy in the Asia and Pacific region.<sup>82</sup>

Using the relational approach, data from national surveys was disaggregated to compare the situations of disabled and non-disabled persons (updated after four years). Ten themes, were selected in discussion with national stakeholders and populated with 31 indicators. The resulting ‘disability index’ (*handicapbarometer*) is an online dashboard, presented as ‘a tool for anyone working within this policy area – from municipal disability councils over public officials to scientists and disability organizations’.<sup>83</sup>

### **The German participation reports**

The development of new disability equality indicators in Germany was led by a government Ministry. The initiative was aligned to the CRPD, mediated by a national disability implementation plan, with oversight from a national scientific advisory board.<sup>84,85</sup> The re-conceptualisation of indicators drew on the UN OHCHR typology with an emphasis on participation outcomes. Like the Danish project, it drew on European disability equality indicators developed by ANED,<sup>86</sup> as well as examples from other fields such as health inequalities, gender equality and so on.

The federal government was obliged by statute (§66 Social Code Book IX) to publish progress reports on the inclusion of disabled people during each term since the 1980s but engagement with the CRPD process stimulated a shift towards ‘participation reports’ (*Teilhabebericht*) newly aligned with it. The 39 indicators were arranged in eight themes, drawing on data from national sources, and published as technical reports of more than 500 pages,<sup>87,88</sup> accompanied by ‘easy-to-understand’ and audio book versions.

### **The Spanish disability observatory**

In Spain, the development of national indicators was led by a State Observatory on Disability (*Observatorio Estatal de la Discapacidad*, OED), established in law as a technical instrument of public administration. In practice it functions as a collaboration between public agencies, civil society and academics. The initiative was aligned the obligations of CRPD implementation (§73, Decree 1/2013) and utilised EU data comparisons.

The system of indicators was designed ‘to measure the degree to which people with disabilities participate in economic and social life’. Based on existing social indicator typologies,<sup>89,90</sup> it covered nine dimensions with 37 indicators, updated annually, where possible.<sup>91</sup> The system is fed by different sources, including disability-specific surveys, disaggregation of general surveys, and administrative records. Since it was launched in 2014, some indicators remain without source data. In most cases, the indicators use the relational approach to compare participation outcomes for disabled persons with the general population, and specifically with women with disabilities.<sup>92</sup> The analysis is presented in technical reports of more than 500 pages, published on the OED website.

## **Disability equality indicators in the UK**

The UK government Office for Disability Issues (ODI) developed a set of ‘disability equality indicators’ before ratifying the CRPD but linked to its Articles via national disability strategy. This occurred at the same time as efforts to develop a broader national Equality Measurement Framework.<sup>93</sup> The disability indicators were developed in consultation with disabled people as ‘a starting point in measuring progress towards disability equality’ and to help monitor progress against national strategy and the CRPD.<sup>63</sup>

The initial presentation adopted a life course approach, from childhood to old age, again comparing mostly outcomes for disabled and non-disabled persons. The initial set used 48 indicators under nine themes, later expanded to 63 and 11 respectively. These were populated by civil servants from national surveys and datasets and updated annually (but not maintained after 2014). Like the Danish example, the presentation used an online dashboard on a government website, as well as summary reporting.<sup>94</sup> At the time of writing this paper a new initiative was launched in the UK to improve disability outcome data and statistics, as the basis for future strategy development and citing the CRPD and SDGs as ‘global drivers for change’.<sup>95</sup>

As shown in [Table 1](#), the most promising examples of indicator development practice in European countries varied considerably in their coverage of different themes relevant to the global governance framework of the CRPD (in some cases the Articles were named, in others implied). Only three Articles were explicitly addressed by all five indicator sets. These were Articles 19, 24 and 27 concerning independent living, education and employment. It may be relevant to note that there was more coverage of social and economic rights than civil and political rights. This might, in turn, reflect the types of public data and social surveys available to disaggregate by disability status (such as Labour Force Surveys, household surveys or administrative registers).

The analysis suggests that over the past decade the CRPD has acted more as a stimulus for voluntary innovation than as a framework of compliance on indicators, whereas the SDG framework anticipates national cooperation in a standardised indicator set (but with little evidence of disability measures so far). On the one hand, this should allay some anxieties about the grasp of quantified technologies on global rights governance. On the other hand, it may frustrate advocates of equality measurement as a lever on state transparency and accountability. National governance may be adapting and responding to transnational obligations but it is not disappearing.

## **Conclusion**

The measurement of group-based inequalities has a long history but it is often difficult to do, and particularly for groups that are weakly defined or poorly represented in official datasets. Disability equality is a relatively latecomer to the field, compared to gender or ‘race’ equality for example. There are also longstanding methodological difficulties in defining and measuring disability equality, and there remains a lack of relevant and reliable data for disaggregation. Nevertheless, there is a rising expectation that disability equality is worth measuring and evidence that it can be done, at least indicatively.

Disability must be considered both as a distinctive dimension of human rights and as a cross-cutting dimension in any general system of equality measurement. The analysis of

social inclusion from a cross-cutting perspective of equality considering disability and gender or 'race' is bringing to light new and productive ways of study known as 'intersectional'.

The CRPD has been a significant driver for some government-led initiatives. Some NHRIs have adopted indicator development within their rights monitoring mandate. Some disabled people's organisations and researchers have used rights-based indicators to hold governments to account in new ways. However, there appear to be no examples of the comprehensive statistical production envisaged in Article 31 CRPD. Global policy frameworks, like the CRPD and the SDGs, may have begun to change the topology of governance towards technologies of governing disability equality from a distance but, so far, national initiatives rather than transnational ones seem to have produced more tangible results. International bodies, like the UN and the EU, have encouraged and supported states to develop quantified technologies of government but there is limited evidence that European states have responded widely or systematically to the invitation. States need to balance fitness for purpose (policy factors) with feasibility (technical factors) and, while transnational actors like the UN and EU can help in both respects, this presents some contradictions for national actors.

On the policy side, international treaty obligations are necessarily comprehensive. National governments prioritise their implementation of such treaties selectively, over discrete terms of government, mediated by national disability strategies and action plans. National authorities are more likely to make selective investments in public statistics that evidence progress against their strategic priorities than to invest in comprehensive statistical databases for periodic reporting to international bodies.

Concerning the global governance framework of the CRPD, it is interesting to note the focus of national governments on limited topics (e.g. independent living, education and employment), which highlights gaps in other dimensions that are equally relevant for inclusive equality. In this sense, further efforts are needed to address lack of attention to outcomes in dimensions like right to life, intimacy, social participation, as well as the intersectionalities of with impairment type, severity, age, gender or ethnicity.

There are also tensions on the technical side. For example, the UN has invested heavily in tools to support states with data definition and collection (such as the ICF typology or the Washington Group question sets). The EU supports its Member States with related, but different, data harmonisation standards (via Eurostat and the European Statistical System). UN effort has focused on exploitation of national Census data. The EU has focused on household social surveys (in which national sub-samples of disabled persons are not large enough to be broken down statistically according to CRPD reporting guidance categories, such as type of impairment). At a national level, there is then a trade-off between granularity of data analysis, data duplication and administrative cost burden (e.g. in demand for new surveys and administrative data). This may accentuate the selectivity of domestic policy-focused indicators.

Despite these tensions, there is great potential for the development of national disability equality indicators that are quantifiable, meaningful for policy makers and useful for monitoring the realisation of international human rights. They need to be designed in a way that contributes to monitoring those obligations (alongside indicators of structure and process) but evidence of inequalities only drives change when it is made visible and acted upon. This requires both strategic prioritisation and public accountability. Rights based statistical indicators need to be made accessible and understandable for



rights holders and defenders (web-based dashboards and easy-to-read factsheets may have more utility for advocates than complex databases or statistical reports, for example). National disability equality indicators must make clear their accountability to the CRPD and SDGs but the political and technical contingencies suggest that these technologies of transnational governance continue to serve more as touchstones for domesticated innovation than as reins of compliance.

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