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Potential, principle and pragmatism in concurrent multinational monitoring: disability rights in the European Union

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Abstract

This article responds to some of the limitations of traditional human rights monitoring systems by identifying the potential for more dynamic methods of recording and reporting rights-based evidence. The paper distinguishes between ‘consecutive’ and ‘concurrent’ models of monitoring and between hierarchical and non-hierarchical monitoring systems. Using the example of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), a principled framework for systems development in this field is outlined. The practical contingencies of designing and implementing new monitoring tools across 34 European countries are then reviewed. The paper concludes that more flexible and dynamic reporting tools can help to make States more accountable for the implementation of their human rights obligations and facilitate policy-exchange and the sharing of good practice. Recent developments within the EU disability field offer potential for adaptation to other human rights fields and to other regions of the world.

1 Introduction

Effective human rights implementation requires effective tools to monitor progress toward the realisation of rights embodied in legal instruments. Within the existing toolkit of rights monitoring, report writing occupies a central, even ‘hallowed’¹ position. Indeed, so heavy has been the emphasis on report-writing that it has been described as a ‘fetish’ in which NGOs and others have indulged at the expense of effective dissemination or impact.² Recent years have witnessed growing interest in the development of rights based measurement indicators.³ The Office of the High Commissioner for Human Rights (OHCHR), at the request of the treaty bodies, has invested considerable effort in this area which has resulted in the publication of an influential indicator framework.⁴

The OHCHR has elaborated a threefold typology of indicators (qualitative and quantitative) for monitoring progress on the realisation of key ‘attributes’ or elements of any human right – namely, indicators of ‘structure’, ‘process’ and ‘outcome’.⁵ These three types broadly correspond to Landman’s division between measurement of human rights in principle, policy and practice.⁶ Thus, ‘structural’ indicators concern ‘the ratification and adoption of legal instruments and [the] existence of basic institutional mechanisms deemed necessary for facilitating realisation of a human right’.⁷ They focus on evidencing the commitment that States have made to relevant human rights, such as ratification of relevant Treaty provisions. ‘Process’ indicators, by contrast, concern the efforts that a State is making to carry out these human rights commitments. An example might be the implementation of a policy or the amount of funding devoted to a particular programme. ‘Outcome’ indicators then ‘capture attainments... that reflect the status of realization of human rights in a given context’.⁸

Despite the impressive efforts devoted to such conceptualisations, de Beco notes that ‘most sets of human rights indicators have never been applied and ... discussions on them seem not to leave the conceptual sphere’.⁹ He suggests that one reason for this is the practical challenge of gathering data to support such indicator systems – a challenge which is heightened in systems that aim to monitor the situation in more than one country. There are also ideological concerns that monitoring based on indicators may lead to an inappropriate reliance on

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quantitative measures in a field driven by its qualitative principles.¹⁰ In addition, as Felner has argued, measures are needed that go beyond confirmation of baseline compliance and that hold states accountable for the progressive and maximum realisation of rights within their available resources.¹¹ Overall, there is widespread consensus that while ‘there are no simple solutions for the human rights measurement problem’,¹² further methodological and technical innovation, combined with careful conceptualisation, is urgently needed.

The field of disability rights provides rich material for examining innovation in rights monitoring because of the catalytic effect of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).¹³ This Convention imposes monitoring obligations on States Parties which, although falling short of some of the proposals made during its elaboration, significantly exceed those imposed by previous human rights treaties.¹⁴ Thus, not only are Parties required to submit to the treaty body a periodic and ‘comprehensive report on measures taken to give effect to [their] obligations...and on the progress made in that regard’¹⁵ but, in addition, they must ‘collect appropriate information, including statistical and research data, to enable them to formulate and implement policies’ giving effect to the Convention.¹⁶ Further, the CRPD requires each Party to designate or establish frameworks (including at least one independent entity) to monitor progress in their implementation of Convention rights.¹⁷ These provisions have intensified the interest in, and urgency for, new monitoring models and tools. The intensification of national monitoring initiatives, together with the common rights framework provided by the CRPD, enhances opportunities for collecting cross-national data and for developing new multinational monitoring tools. Multinational efforts are not substitutes for national monitoring effort.¹⁸ Indeed, they may strengthen national data-collection processes by prompting efforts to gather information on issues traditionally neglected.

It is against this background that we introduce recent innovations in ‘concurrent multinational monitoring’ in which we have played a part.¹⁹ The immediate context is that of disability rights in the European Union (EU) but the lessons learned have wider application. We argue that concurrent multinational monitoring tools, if grounded on appropriate principles and supported by appropriate technologies, offer significant advantages over conventional report-based tools. Concurrent multinational monitoring, grounded in a dynamic evidence base and facilitated by internet technologies, can assist in holding States accountable for the effective implementation of human rights obligations and support processes of mutual learning and good practice sharing.

This paper is divided into four main sections. First, the distinguishing features of concurrent multinational monitoring are established. This is followed by reflection on the potential benefits it could offer. The third section outlines core principles which we have identified as those which should underpin an idealised system of concurrent multinational monitoring in the disability field. The fourth section then examines the systems in the EU, with particular attention being given to statistical Indicators of Disability Equality in Europe (IDEE) and a novel database reporting tool ‘The Disability Online Tool of the Commission’ (DOTCOM).²⁰ The development of these two systems represents a pragmatic effort to apply innovative monitoring methodology in practice and is part of an on-going venture with potential for enhancement through the addition of further evaluative mechanisms. The conclusion evaluates progress against the principles previously identified and assesses the extent to which the EU experience may provide useful lessons for the development of more dynamic concurrent multinational monitoring tools beyond the disability field and in other regions of the world.

2 The characteristics of concurrent multinational monitoring

Multinational rights monitoring models may be broadly ‘concurrent’ or ‘consecutive’ in approach. Consecutive multinational monitoring gathers, presents or scrutinises data relating to particular countries (or groups of countries) sequentially.²¹ Concurrent multinational monitoring, as the name suggests, is concerned with evidencing the state of affairs in more than one country simultaneously.

Typically, the consecutive model is marked by a periodic cycle in which individual country reports are reviewed in turn, on a recurrent basis. In the disability field, the mechanism adopted by the UN Committee on the Rights of Persons with Disabilities²² is the most high profile example, and is characteristic of similar processes whereby a supranational body is charged with detailed examinations of national situations on which it offers advice or recommendations.²³ The system is also hierarchical in that national governments have, through treaty ratifications, agreed to the supervisory role of the supranational body in question. However, consecutive multinational monitoring may also be carried out in non-hierarchical contexts, without the formal consent or co-operation of national governments. In the disability field, the activities of Disability Rights Promotion International (DRPI) provide one such example.²⁴

Concurrent multinational monitoring, by contrast, brings together data from all the countries being monitored simultaneously and continuously. In such a system, scrutiny does not necessarily rotate between countries, or groups of countries, but may be focused equally or differentially on all or any countries at any point in the monitoring process. Examples of non-hierarchical concurrent multinational monitoring include the Freedom Index,²⁵ the European Gender Equality Index²⁶ and, in the disability context, the International Disability Rights Monitor (IDRM) - although, as yet, IDRM has collected national data within each region only once. A concurrent monitoring system should thus be distinguished from a one-off cross-sectional reporting exercise, such as a multinational study conducted at a specific point in time. For example, the World Health Organisation's *World Disability Report*²⁷ can be viewed as an ambitious cross-sectional report on the global state of affairs although it is not yet an on-going concurrent monitoring venture. A concurrent system would allow changing data from any country to be updated and reported as developments occur.

Examples of hierarchical concurrent monitoring are less easy to identify. This is largely because the hierarchical systems have tended to adopt consecutive report based systems (although the development of comparative rights based measurement indicators would offer concurrent observations of a quantitative kind). There are good pragmatic reasons for this historic preference. Consecutive monitoring allows limited expert resources to be focused intensively on individual countries in turn, facilitating a deeper scrutiny than would be possible if scarce resources were constantly divided between countries. Further, the overarching aim of most hierarchical human rights monitoring systems is to assess the totality of progress being made within each particular country rather than how its progress compares with that being made in other countries. However, despite these advantages, there are also problems - particularly where over-burdened and under-resourced systems result in delays in scrutiny and accountability (e.g. we estimate the likely time from submission of State Parties' reports to their scrutiny by the UN Committee on the Rights of Persons with Disabilities may now be approaching seven years). Unsurprisingly, such difficulties have resulted in calls for reform of the UN human rights monitoring mechanisms.²⁸

Concurrent multinational monitoring models offer an alternative way of collecting and presenting human rights data. In principle, such systems could combine the rich evidence base offered by 'hallowed' country reports with the structured comparison of rights based measures, utilising both qualitative and quantitative evidence in a responsive and flexible reporting tool. This, in effect, is the methodological challenge to which we address this paper.

3 Potential: the added value of concurrent multinational monitoring

As previously noted, multinational monitoring systems cannot replace national monitoring responsibilities entirely and the importance of strong national engagement cannot be overstated.²⁹ Neither should concurrent multinational systems be regarded as replacements for the detailed and hierarchical scrutiny of each individual country, as by the UN Committee on the Rights of Persons with Disabilities. Further, as the Office of the OHCHR has pointed out, an 'index to rank countries according to their human rights performance' is not 'necessarily desirable'.³⁰ Ranking systems are likely to be resisted by national governments for political

reasons; they may fail to take account of important contextual differences between different countries (including resource capacity); and they risk giving the impression to strong performers that continued effort in progressive realisation of human rights is not a priority.³¹ While accepting the validity of such concerns, we argue that there are significant potential benefits in developing dynamic concurrent multinational monitoring tools which incorporate qualitative information (including descriptions of relevant policies, laws and other measures as well as evaluations of impact and effectiveness) and thus go beyond the traditional conception of them as quantitative measurement indicators.

Two principal objectives of human rights monitoring systems may be identified, in the disability field and more generally.³² First, in relation to governments, to help identify problem areas, to inform the development of more evidence-based policies and to make transparent any areas of inaction or retrogression. Second, in relation to non-governmental actors, to inform and strengthen their efforts to challenge human rights violations and to work for social change. Concurrent multinational monitoring has the potential to make a significant contribution to the fulfilment of both these objectives. .

Taking the first objective, drawing together analogous information from different countries about the situation of disabled people and the protection of their rights could provide national governments with additional incentives to implement reform and to identify innovative and promising practice.³³ This potential is enhanced where there is also opportunity for multinational intervention or dialogue on human rights issues (for example, at the EU level). In such contexts, comparable cross-national data has added value in identifying priorities, trends and examples of good practice to shape regional policies as well as national ones. In this regard, the EU possesses relatively strong mechanisms that may shape legal and policy development (including through processes of mutual learning and good practice sharing) in its 28 Member States. The 'competences' of the EU to legislate and to initiate policy are defined in its foundational treaties – consolidated in the Treaty on the European Union and the Treaty on the Functioning of the European Union) and the relationship between these competences and the policy areas covered by the CRPD is set out in Annex II of the European Council's 2009 Decision authorising EU conclusion of the CRPD.³⁴ The fact that the EU has ratified the CRPD, alongside the vast majority of its Member States, poses new and challenging questions as to the precise boundaries between EU and Member State competences in the disability field.³⁵ For present purposes, it suffices to say that EU countries ratifying the CRPD thereby submit to hierarchical monitoring by the UN Committee in a broader range of policy domains than those for which they have agreed to hierarchical monitoring by the EU. EU efforts to monitor progress in disability rights implementation is therefore subject to limitations, the negotiation of which calls for a significant degree of political pragmatism.

Taking the second objective, concurrent models of multinational monitoring also have the potential to provide information useful to national, regional and international non-governmental organisations (NGOs) in their efforts to campaign for CRPD-inspired laws, policies and programmes. For instance, multinational monitoring tools might reveal, in a timely way, how the legal or policy approach of one country compares with others on the same issue (e.g. in guardianship and legal capacity legislation or reasonable accommodation and non-discrimination laws). NGOs, like governments, would be assisted by concurrent multinational evidence to identify examples of promising practices or poor performance that could shape their lobbying efforts and policy claims.³⁶ However, in any kind of system, the value to NGOs of evidence remains contingent on its underlying veracity and its accountability to civil society (e.g. through some form of shadow reporting).

In summary, concurrent models of multinational monitoring offer the potential for added value over established systems of consecutive country reporting. This potential is particularly potent in contexts where regional multinational action on human rights is also possible, such as in the EU. However, there are practical and political limitations and the extent to which any new system might fulfil its potential will depend on pragmatism as well as principle. The following section outlines five basic principles, relevant to other rights monitoring models but particularly

pertinent to the development and implementation of a concurrent multinational monitoring system. These are derived and developed from a systematic analysis of disability rights monitoring mechanisms conducted in 2008 as part of the work of the European Academic Network of Experts on Disability (ANED).³⁷

4 Principles: the basis for an effective concurrent monitoring system

The five key principles for an effective rights monitoring system in the disability field are: the involvement of disabled people; sensitivity to intersectionality and inclusiveness; a focus on disabling barriers; comparability over time and between countries; and effective public dissemination.

4.1 Involvement

Fundamental to the CRPD is the notion that disabled people should be fully involved in all aspects of its implementation.³⁸ This is unsurprising given the unprecedented involvement of civil society (particularly disabled people's organisations) in the elaboration of this Convention.³⁹ Thus, Article 4(3) requires States Parties to 'closely consult with and actively involve' disabled people, through their representative organisations, in 'the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning' them. Further, as regards monitoring, Article 33(3) requires that 'civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process'. As well as being required by the CRPD, the full involvement of disabled people and their organisations in monitoring systems is likely to enhance the effectiveness of those systems – a point stressed by international disability rights monitoring projects such as IDRM⁴⁰ and DRPI.⁴¹ An effective concurrent multinational monitoring system thus requires some facility for the active input of civil society actors, and in particular disabled people's organisations.

4.2 Intersectionality and inclusiveness

The 'disabled' population includes people with all types of impairment, of all ages, genders, sexual orientations, religions and ethnicities, situated in all types of living arrangement. CRPD rights are conferred on all and it is essential that monitoring seeks to be sensitive to difference and intersectionality.⁴² Indeed, the CRPD attaches more explicit importance to intersectionality than previous UN human rights treaties, reflecting the development of a more multidimensional conception of equality in UN human rights law.⁴³ Thus, for example, Articles 6 and 7 of the CRPD require consideration of the particular situation of disabled women and children in implementation efforts and Article 31(2) requires that data collected by States Parties should be capable of disaggregation. The Reporting Guidelines of the Committee on the Rights of Persons with Disabilities specify that periodic State reports 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.⁴⁴

This guidance sets a high standard not met in any of the State reports considered by the Committee to date. Indeed, it benchmarks an ideal that all countries will struggle to achieve. Nevertheless, it represents a goal toward which State Parties (and the EU⁴⁵) must attempt to move and a principle that should be reflected in the development of any effective system of concurrent multinational monitoring.

4.3 Disabling Barriers - a social model approach

Difficulties in defining 'disability' are illustrated by the fact that the English language version of the CRPD uses the term 'persons with disabilities' while Anglophone proponents of the social model of disability (including ourselves) more often refer to people regarded as having 'impairments' and reserve the term 'disability' for the exclusionary effects that socially created barriers impose upon them.⁴⁶ Nevertheless, the CRPD explicitly recognises the disabling impact of societal barriers on people with 'impairments',⁴⁷ and draws inspiration from a broad social model approach.⁴⁸ Thus, someone with impairment may become 'disabled' as a consequence of their encounters with societal barriers but, in an idealised society where such barriers were absent, might cease to be disabled. The progressive realisation of human rights for disabled people thus requires actions that identify and eradicate the barriers to full participation and equality for all people with impairments in society.

Comparing 'disability' in different countries, from a social model perspective, is then markedly different from comparing the prevalence of impairments. It requires comparison of participation barriers and identification of equality gaps that exist between people with and without impairments (as well as analysis of the actions being taken to remove barriers and close the gaps). Achieving comparable data on such issues from different countries depends on the extent to which comparable barriers, comparable groups of people (with and without impairments) and comparable outcomes can be evidenced in the available data.

4.4 Comparability

The OHCHR has emphasised that indicators should be sensitive to the socio-economic context of the countries to which they are applied. Thus, indicators appropriate for a relatively wealthy industrialised country might have less relevance to a poorer one.⁴⁹ However, in systems of concurrent multinational monitoring, where cross-country comparison is particularly important, there is a case for arguing that context sensitivity should not result in different indicators being used for different countries within the same system. Such sensitivity should be incorporated into the selection of the indicator set but the set should, ideally, apply to all the countries involved. In the case of comparison between countries within the EU, there are strong arguments for a consistency of approach.

The comparability of data between different countries underpins the success of any multinational monitoring system⁵⁰ but is particularly salient to achieving the potential of concurrent monitoring (e.g. it is more critical to the conceptualisation of cross-sectional indicators than to isolated country reports). However, collecting comparable evidence on disability rights poses some particular challenges, arising from national differences in identifying and defining disability, disabled people or disability law and policy, as well as differences in national monitoring methods and infrastructures.⁵¹

The comparability of progress over time is also relevant, notably in reporting progress using outcome indicators.⁵² At the outset of longitudinal or time-series monitoring it is necessary to establish baseline measurements and appropriate indicators against which to measure future progress. Comparisons of progress then require monitoring to be conducted periodically on an on-going basis. Ideally, monitoring becomes 'not a snapshot but an on-going video'.⁵³ The consecutive monitoring of country reports (as in the UN Committee model) offers a series of 'freeze frame' snapshots over the long term but a concurrent multinational monitoring system should arrive closer to the video analogy.

4.5 Dissemination

Article 31(1) of the CRPD requires States Parties to 'collect appropriate information, including statistical and research data' and Article 31(3) requires them to 'assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others'. Although only 'statistics' are mentioned here, Article 31(1) refers also to 'research' and 'appropriate information', where the obligation to disseminate would also seem relevant.

The importance of effective dissemination cannot be overstated. Making relevant monitoring information available to legislators and policy-makers is a pre-requisite for the

development and evaluation of effective evidence-based policies. Making it available to disabled people, their organisations and civil society at large is a pre-requisite for public accountability and democratic engagement. Without an effective sharing of evidence, States cannot realise their obligation to fully involve disabled people in either monitoring or policy development.

The dissemination of data collected through concurrent multinational monitoring systems raises challenges – particularly where a large number of countries (and languages) may be involved. If these challenges can be overcome, however, the dissemination of more plural and dynamic data has some advantages over the publication of country reports.⁵⁴ Web technologies provide an obvious means to present and disseminate dynamic datasets in new ways and to support stakeholder engagement.⁵⁵ However, as with any dissemination format, effectiveness will also depend on their accessibility and usability by people with different types of impairment or language.

5 Pragmatism: concurrent multinational monitoring in the European Union

The remainder of this paper considers recent developments in concurrent multinational monitoring of disability rights within the EU, in light of the context and principles set out above. This section will first review some of the specificities of disability rights monitoring, on the basis of a social model approach. It will then consider how the distinctive EU context provides an opportunity structure for multinational monitoring and dissemination. The discussion will then move to examine the concurrent multinational monitoring tools recently developed under the auspices of ANED - Indicators of Disability Equality in Europe (IDEE) and the Disability Online Tool of the Commission (DOTCOM).

5.1 *Rights based measurement in the disability field*

The OHCHR guide to measurement and implementation in human rights monitoring did not address disability-specific issues in any depth, but, as we have proposed elsewhere⁵⁶ disability rights indicators may also be divided into three types that are broadly analogous to those proposed in its structure, process and outcome model (outlined at the beginning of this paper). Thus, particularly relevant in the disability field are indicators of entitlements as far as they exist in law or policy; indicators of accessibility, which evidence the accessibility of for instance goods, information, technologies, public transport vehicles and the built environment to people with impairments; and indicators of participation, which evidence the relative participation rates of people with impairments in key domains of every-day life. The first of these, indicators of rights in law, corresponds to OHCHR structural indicators. Indicators of accessibility and indicators of participation generally take the form of OHCHR process and also outcome indicators.

Taking these three types of disability equality indicator in reverse order, participation outcomes are clearly relevant to the realisation of specific CRPD rights (e.g. indicators of educational attainment or employment rates). Indeed, participation, inclusion and equality are fundamental principles of that instrument.⁵⁷ Measuring the participation gap experienced by people with impairments, when compared to people without impairments, raises the thorny question of identifying who is to be counted in each group. Thus, (unlike the indicators of accessibility, discussed below) participation indicators also requires identification of their impairment status.

The Washington City Group on Disability Measurement⁵⁸ (which reports to the UN Statistical Commission) has been working for the past decade to improve cross-national comparability in such statistics. Difficulties remain, however,⁵⁹ as national administrative definitions of ‘disability’ vary considerably. The usual approach is through standardised questions in general population surveys, which ask respondents if they regard themselves as having certain forms of functional or activity limitation. This is the approach currently favoured by the Washington Group⁶⁰ but its recommended questions often fail to distinguish between the limitations of impairment and the disabling effects of barriers (in the form of e.g. lack of

accessibility or lack of personal assistance schemes). For example: 'Do you have difficulty (with self-care such as) washing all over or dressing?' and 'Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?'

It is easy to imagine the dilemma posed by such questions.⁶¹ A person with a physical impairment may have difficulty in dressing or washing if unassisted but, when provided with adequate support (in the form of assistive devices or of personal assistance), may report no difficulty. Similarly, a person who uses sign language may have no difficulty communicating with someone who understands sign language but may otherwise experience considerable obstacles. Moreover, impairment and functional limitation are contested concepts embedded in social context, and cultural differences affect self-reporting and thus comparability between countries. It is important for such data limitations to be acknowledged.

A more sophisticated form of survey questioning has been piloted in recent years, in which self-identification of difficulties experienced in daily life might be separated from their perceived causes.⁶² For the moment, however, participation outcome measures in EU countries are largely dependent on the self-categorisation of survey respondents into those who do state that they are limited in everyday activities by a long-term impairment or health condition, and those who do not.

Our second type of disability equality indicator seeks evidence of accessibility (a focus demanded by the principle of a social model approach, outlined earlier). Disability data systems have traditionally tended to focus on counting disabled people and their participation but overlooked the measurement of barriers to accessibility, attracting criticism from social model advocates.⁶³ The relevance of measuring social and environmental barriers was acknowledged by the World Health Organisation when, in 2001, it adopted environmental classifications within its International Classification of Functioning, Disability and Health (ICF).⁶⁴ New codes were introduced to enable classification of products and technology, natural and built environments, support and relationships, attitudes, and services, systems and policies. These could be combined with a grading scale for the 'extent of influence on functioning' but, unlike the social model approach, the ICF conceptualises environmental factors as contextual rather than as the primary causal factor in the creation of disability. The WHO typology is oriented to epidemiology rather than to rights, and predates the CRPD. A more rights-based approach to classifying disabling barriers is needed, drawing out the explicit rights to accessibility conveyed within that instrument. The first type of disability rights indicator, rights in law requires less explanation. The primary concern here is to evidence, often qualitatively, what the OHCHR terms the 'basic institutional mechanisms' that exist in the disability field. The Articles of the CRPD provide a clear reference point to help identify how these might be classified and defined, as we have shown elsewhere.⁶⁵ We turn now to the contingencies of monitoring these types of rights within the EU context.

5.2 *The contingencies of EU-level monitoring*

There is long-standing precedent for EU level data collection and monitoring of policies and outcomes in the Member States but the growing interest now attached to disability monitoring is driven by implementation of the European Disability Strategy 2010-2020.⁶⁶ This Strategy is oriented to facilitating implementation of the CRPD within the EU. One of its specific objectives is to establish appropriate governance structures to support this process, including by:

Significantly improving monitoring and evaluation by: creating conditions for improving the quality and comparability of data; developing relevant indicators and possibly common targets; collecting reliable data and statistics.⁶⁷

As suggested earlier in this paper, multinational monitoring offers the potential for added value in the context of an established regional organisation like the EU. It would enable the European Commission to facilitate the sharing of promising practices amongst its Member

States, to review where targeted advice is needed, and to propose new EU legislation or enforcement actions within its areas of competence. For example, mapping and monitoring the implementation of disability rights in the EU Member States can assist in monitoring the transposition of relevant EU law (e.g. the Employment Equality Directive⁶⁸ prohibiting disability discrimination in employment and occupation, or various transport Regulations that impose accessibility, non-discrimination and assistance requirements⁶⁹). In such areas EU monitoring becomes hierarchical, but non-hierarchical monitoring is equally important to the attainment of EU strategic objectives and, for this reason, monitoring in policy areas beyond those in which EU law imposes obligations on Member States is nevertheless often supported by EU institutions. Thus, information gathered through collaborative, but non-binding mechanisms, plays an important role in assessing the effectiveness of current EU strategies and in shaping policy.⁷⁰ Tools for concurrent multinational monitoring of disability rights at EU-level must be developed with sensitivity to this legal and political context.

5.3 EU-level monitoring mechanisms in the disability field

A number of structures support the monitoring efforts of the European Commission in relation to disability rights. One of these is the European statistical agency Eurostat (one of the Commission's Directorates General), which has responsibility for the provision of relevant statistical information to help 'define, implement and analyse Community policies'.⁷¹ The European Disability Strategy contains a series of commitments designed to strengthen disability-related statistics, through the work of Eurostat.⁷²

In addition, the Commission has established two relevant networks of independent experts, largely consisting of university academics, to provide it with information and analysis – the European Network of Legal Experts in the Non-Discrimination Field (the Legal Network)⁷³ and the European Academic Network of Experts on Disability (ANED)⁷⁴. The former addresses progress toward implementation of non-discrimination and equality law, on a range of grounds, one of which is disability. The latter focuses exclusively on disability and although 'academic', includes strategic input from the European Disability Forum⁷⁵ and Age Platform Europe.⁷⁶ ANED addresses a range of policy issues of interest to the Commission and across the 34 EU Member, Candidate and Associate countries. It provides analysis on the extent to which disability is mainstreamed within EU legislation, statistics and policy exchange.⁷⁷ It publishes a range of quantitative and qualitative evidence relevant to disability rights monitoring.

Finally, the EU Agency for Fundamental Rights (FRA) was established in 2007 to provide EU institutions and Member States with 'assistance and expertise relating to fundamental rights'.⁷⁸ Unsurprisingly, its tasks include the collection, recording, analysis and dissemination of 'relevant, objective, reliable and comparable information and data'⁷⁹ and the development of methods and standards 'to improve the comparability, objectivity and reliability of data at European level'.⁸⁰ Its first disability project ran from 2009-2012 and resulted in the publication of a number of reports on the rights of people with mental health conditions and people with intellectual impairments.⁸¹ As yet, FRA has not developed standardised indicators for use in monitoring disability rights, although it has begun to do so for children's rights.⁸² Its 2011 annual conference focused on the topic of fundamental rights indicators and their development seems likely to become an important part of FRA's future work.⁸³ In 2012, the EU confirmed FRA as an independent body within the co-ordination mechanism required by Article 33 of the CRPD to monitor EU implementation of the CRPD. The monitoring of disability rights within the EU will thus become an increasing focus of FRA's work in coming years. It is already collaborating with ANED in the development of relevant monitoring indicators.

As noted at the outset, one of the limitations of traditional monitoring systems has been reliance on static outputs. In the EU disability rights context, monitoring has typically taken the form of country reports and synthesis report documents uploaded to archive websites of the Commission or its networks. One of the principle drawbacks of such reports is their lack of responsiveness to new developments – with the result that they become quickly out of date as they are overtaken by legal and policy changes. Further, the data gathered by different

networks or studies has been published in different places with no central point of access. The EU and its associated expert networks have collected a wealth of concurrent multinational data but limitations in updating facilities and in dissemination strategies have meant that the resulting evidence base has remained somewhat sporadic and fragmented. The next section will introduce tools recently developed under the auspices of ANED, in consultation with a range of stakeholders, that demonstrate the potential for an alternative, more dynamic approach to concurrent multinational monitoring.

5.4 New tools for concurrent multinational monitoring

As mentioned above, a key commitment in the European Disability Strategy is to improve EU-level disability rights monitoring. Prior to the current 10-year Strategy and the EU's ratification of the CRPD, Eurostat had been pursuing the potential for greater data harmonisation and integration of disability statistics in the EU surveys (e.g. via the European Statistical System and the UN Washington Group). At the same time, from 2008, ANED had also engaged in the scoping and conceptual development of disability indicators (as one strand in a larger work programme). The research began in 2008 with a review of emerging methodologies being used by other rights monitoring initiatives internationally.⁸⁴ At the same time, a systematic review was conducted to identify relevant data sources, with a focus on quantitative datasets of European comparative value.⁸⁵ Key findings and recommendations were discussed with network researchers from 29 countries, representatives of disabled people's organisations and European Commission staff at the end of 2008.⁸⁶

The next stage, in 2009 (also prior to the new European Disability Strategy), was the conceptualisation of qualitative and quantitative rights based indicator proposals, consistent with the CRPD.⁸⁷ These were framed as 'Indicators of Disability Equality in Europe' (IDEE) arising from a working group including representatives of ANED, Disabled People's International, the World Health Organisation and Eurostat, and consultation with the Council of Europe working group on disability indicators, the European Disability Forum, the European Forum of Sign Language Interpreters, and other academics working in the development of comparative indicators. Proposals for quantitative disability indicators focused firstly on mirroring the main participation measures in the framework of the EU's Europe 2020 Strategy⁸⁸ – focusing on equality gaps for disabled people in education, employment and poverty. Nine core items are updated each year, with supplementary or demonstration indicators in new topic areas (e.g. accessibility or political participation). Thus, the IDEE framework provides some foundation for concurrent multinational monitoring through outcome indicators.⁸⁹ Up to this point, the qualitative dimension remained 'report' based.

In the third phase, during 2010-2011, the statistical development continued under the original IDEE title. In addition, work began on a new web-based policy mapping tool in support of the emerging European Disability Strategy. The Commission had pledged to introduce such a tool and it was envisaged that this would provide a structured, comparable and public record of the legal and policy measures adopted by each Member State, and by the EU, to implement the CRPD. Country level data would be collected, initially by ANED, with national governments having the opportunity to validate evidence relating to their country. A future mechanism enabling stakeholder organisations (notably disabled people's organisations) to comment on the effectiveness of the measures reported was also envisaged.⁹⁰

Following initial design and testing in 2011, and consultation with members of the EU High Level Group of states representatives in the disability field, this was published as the 'Disability Online Tool of the Commission' (DOTCOM) in May 2012.⁹¹ It was populated with data collected from 30 European countries, to which data from a further four countries has since been added. It should be noted that DOTCOM is an instrument of non-hierarchical monitoring, funded in its development by the European Commission, but maintained independently by ANED.

In its current form, the database contains descriptive data on relevant laws, policies and programmes, for each country and for the EU, against 43 items selected as relevant to implementation of the CRPD and within the scope of the European Disability Strategy. These 43

items are divided into eight themes or headings, including: the status of the CRPD; the general legal framework for disability rights; accessibility legislation and standards; policies supporting independent living; education and training; employment; provisions for the collection of disability statistics and data; and, finally, awareness-raising, training and international action.

Under each theme there are currently between three and nine items— each one representing a specific action or obligation placed on States Parties to the CRPD. Thus, for example, Theme A (UN Convention status) follows the style of OHCHR ‘structure’ indicators, to establish: the country’s ratification of the CRPD (A1) and Optional Protocol (A2), any interpretive declarations, reservations and objections (A3); its implementation of a comprehensive legislative review (A4); its establishment of the required focal point (A5); its governmental coordination mechanism relating to disability(A6); its independent monitoring mechanism (A7); its submission of official reports to the UN (A8); and, any known shadow reports (A9).

For each individual item, there is a factual summary description, written in English, with supporting web links to national legislation, official sources or other documented evidence. In total, the DOTCOM database describes and evidences more than 1,500 distinct policy measures across 34 countries and the EU (a combined account in excess of 300,000 words with more than 3,000 supporting links to primary sources). Its immediate benefit since 2012 has been an unprecedented new level of access to knowledge about disability policies in European countries (for policy makers and also for civil society, researchers and the general public).

Its second benefit, as alluded to earlier, is that DOTCOM differs from a traditional repository of country ‘reports’ through its use of a relational database architecture with options for concurrent updating, scrutiny and reporting. Its innovative architecture for data management and retrieval combines the advantages of concurrent monitoring (any individual item from any country may be updated at any time) with the familiarity of traditional ‘reports’ (the data can be combined and exported in ‘country report’ form, as well as other forms).

Thus, the web interface, its underlying database and content management system allows individual items or supporting references to be updated by the contributing experts without the need to rewrite or republish whole country reports. It allows end users to make bespoke searches and to compile cross-tabulated reports suited to their specific needs. For example, an end user can compile and download a ‘country report’ (e.g. containing structured national evidence on all 43 items for ‘Slovakia’), or a thematic report (e.g. containing evidence on three ‘Transport Accessibility’ items for ‘EU Member States’), or any combination of multiple items and countries. Any of these reports can be exported in document (Word, PDF) or tabulated (Excel spreadsheet) form. In principle, if the data can be maintained, such a system would allow for scrutiny of the state-of-play in any country at any time. Information about what changes have been made over time in any particular country is, however, not publicly available through DOTCOM – although details of changes are recorded, thereby creating the possibility of enabling such longitudinal searches in the future.

The publication of DOTCOM represents the culmination of a considerable amount of work by many people over a period of several years. However, it is in its early stages. Three main respects in which it might be further developed can be identified. First, DOTCOM does not yet include the facility to enable disabled people’s organisations, or other stakeholders, to enter evaluations of the effectiveness or impact of an item in the database (although the technical facility exists to allow comments or document uploads, such as shadow reports, to be attached to any country-specific item). It is to be hoped that it will be feasible to realise the Commission’s original vision by the addition of this feature, which would greatly enhance the value of the tool. Without it, the principle of ‘involvement’, outlined earlier, will not be fulfilled.

The addition of such a facility would require pragmatism and a consideration of practicalities. Allowing any visitor to the site to add comments would undermine the authority and validation of the data (although it might be possible to develop open forums outside but in parallel with the structure of the tool). A pragmatic approach in the EU disability context might be to grant contributor rights to the umbrella disability organisations of each country and of the

EU (for example, represented by the full member national councils and full member NGOs of the European Disability Forum). In an ideal world, where resources were plentiful, the tool would also be made available in the languages of all its constituent countries (in the case of DOTCOM, translation and updating in all of the EU's 25 languages would be a challenge beyond current resource allocation).

Second, the 43 policy items already included in DOTCOM are loosely linked to the 'areas for action' in the European Disability Strategy 2010-2020. DOTCOM thus operates more explicitly as a monitoring tool for the EU Strategy than for the CRPD in its entirety. Significant CRPD obligations (such as access to justice) do not yet appear in DOTCOM. There is no technical reason why the current typology should not be expanded, if political consensus and resources for the collection and processing of additional data could be delivered.

Third, the dynamic reporting of qualitative data provided by DOTCOM could be linked to statistical outcome data of the kind piloted via IDEE (and where possible, disaggregated by sex, age, ethnicity, type of impairment, etc). Such an integrated system would go a considerable way to fulfilling the vision of the OHCHR, as well as the potential of a concurrent multinational system. While the data challenges are considerable, this has not deterred the EU from funding an innovative development with a pragmatic acceptance that indicator systems are 'learning-by-doing instruments'.⁹² This acceptance, it is hoped, will help to ensure that in the not-too-distant future such tools can be enhanced in the ways suggested here.

6 Conclusion

In human rights monitoring, there is both an appetite and a need for new systems and tools. In this article, we have explored the potential contributions of concurrent multinational monitoring and outlined the principles underpinning the development of any such system in the field of disability. Those principles were used to frame the development of IDEE and DOTCOM and they continue to provide inspiration for the on-going refinement of these tools. Both DOTCOM and IDEE have made new and valuable contributions to disability rights monitoring in Europe, in terms of methodology and content. DOTCOM, in particular, illustrates how concurrent multinational monitoring can be enhanced by interactive web technologies that move authorship, scrutiny and dissemination beyond the static reporting models on which so much reliance has hitherto been placed.

Nevertheless, these tools are in development and our aim (resources and capacity permitting) is to move closer toward an integrated system of mapping and monitoring, in which qualitative and quantitative evidence can be combined and in which all five of the principles outlined in Section 4 are fulfilled. Integrating DOTCOM and IDEE would provide more direct links between evidence of structure and process (e.g. employment policies and programmes) and outcome indicators (e.g. employment rates) and come closer to the integrated indicators approach advocated by OHCHR.⁹³ Alongside statistical indicators of outcome, it will be important to devise a facility to input evaluative evidence from disabled people's organisations, and perhaps other civil society actors. However, these aspirations notwithstanding, a valuable and significant exercise of 'learning by doing' is now well underway. The advent of tools such as DOTCOM heralds a new era in disability rights monitoring. It provides a central access point for data on a wide range of issues, and a dynamic structure for bespoke data retrieval and reporting. It offers the potential for up-to-date knowledge about the realisation of rights, which the addition of outcome and evaluation evidence would greatly enhance.

The process of conceptualising and developing DOTCOM and IDEE has been interesting and challenging. It has demonstrated the importance of collaboration across disciplines⁹⁴ (expertise in law, social policy, statistics and engineering all being essential) and collaboration across countries (requiring, as it has, expertise in the legal and policy developments of 34 countries). It owes much to the European Commission's entrepreneurship and commitment to multinational monitoring in the disability field. It is likely that national governments may, initially at least, be reluctant to participate in concurrent multinational monitoring tools precisely

because of their potential to facilitate comparisons of human rights performance. The involvement of independent experts (from academia or NGOs) is therefore likely to remain key to the establishment and maintenance of such systems.

These considerations provide useful information for those seeking to develop similar tools in other contexts. Within the EU, factors that have nurtured the development of DOTCOM might also be used to nurture similar concurrent monitoring tools in contexts such as gender equality or Roma inclusion. The EU's ratification of the CRPD has provided a powerful incentive to enhancing monitoring efforts in the disability field but the disability experience could now be used as an example to inspire the development of similar monitoring tools in other fields. Beyond the EU, concurrent multinational monitoring tools such as DOTCOM might also prove helpful. Collaborative working and funding are pre-requisite to any such enterprise. It may, however, be possible to build on existing networks and to reduce expenditure by, for instance, populating benchmark information from reports already submitted by States and civil society to relevant treaty monitoring bodies. In time, the increased availability of such data might well motivate national governments to collaborate with database managers to ensure that entries relating to their countries are free from inaccuracies and up-to-date. In this way, it is possible to imagine similar concurrent multinational monitoring tools coming into existence without excessive cost.

To conclude, concurrent multinational monitoring of disability rights in the EU has entered a new phase with the publication of DOTCOM. Further work and development is needed to ensure that underpinning principles are more fully substantiated and its long-term value will depend on the extent to which it can be maintained and developed within the resources and political contingencies of the EU. Nevertheless, it already offers a pragmatic solution to the difficulties identified in previous EU monitoring efforts in the disability field. In the current hunt for new and innovative human rights monitoring tools it offers an important contribution – facilitating cross-country comparisons and the sharing of good practice. It demonstrates the potential for a more dynamic method of collecting and disseminating evidence in human rights monitoring systems. Web-enabled database technologies, and collaborative working environments, have the potential to replace the fixed structures of traditional 'report' systems with more dynamic and participatory alternatives. We would urge human rights organisations, academics and monitoring bodies to give serious consideration to these options.

¹ P Gready, 'Reasons to Be Cautious about Evidence and Evaluation: Rights-based Approaches to Development and the Emerging Culture of Evaluation', *Journal of Human Rights Practice* 1 (2009): 380.

² Ibid.

³ For an excellent review of the range of work conducted in this field (together with helpful analysis and critique) see T Landman and E Carvalho, *Measuring Human Rights* (London: Routledge, 2010).

⁴ OHCHR Human Rights Indicators: A Guide to Measurement and Implementation (New York/Geneva: UN, 2012) HR/PUB/12/5; OHCHR, *Report on Indicators for Promoting and Monitoring the Implementation of Human Rights* (New York/Geneva: UN, 2008) HRI/MC/2008/3; OHCHR, *Report on Indicators for Monitoring Compliance with International Human Rights Instruments* (New York/Geneva: UN, 2006.) HRI/MC/2006/7.

⁵ OHCHR (2012), above n 4, and Office of the High Commissioner for Human Rights, *Report on Indicators for Promoting and Monitoring the Implementation of Human Rights (HRI/MC/2008/3), 20th meeting of chairpersons of the human rights treaty bodies* (Geneva: UN, 2008).

⁶ T Landman, 'Measuring Human Rights: Principle, Practice, and Policy', *Human Rights Quarterly* 26(4) (2004): 906. See also Landman and Carvalho, above n 3.

⁷ OHCHR (2008), above n 4: para 18.

⁸ OHCHR (2008), above n 4

⁹ G. de Beco, 'Human Rights Indicators: From Theoretical Debate to Practical Application' *Journal of Human Rights Practice*, 5 (2013): 380.

¹⁰ R. Archer, 'Introduction to the Special Issue: Where is the Evidence?', *Journal of Human Rights Practice* 1 (2009): 333

¹¹ E. Felner, 'Closing the "Escape Hatch": A Toolkit to Monitor the Progressive Realization of Economic, Social, and Cultural Rights', *Journal of Human Rights Practice*, 1 (2009): 402.

¹² Landman and Carvalho, above n 3, p. 131.

- ¹³ See further M Rioux, P Pinto and G Parekh (eds) *Advancing Rights: Politics of Disability, Monitoring and Social Change* (Toronto: Canadian Scholars Press/Disability Rights Promotion International, 2014).
- ¹⁴ See generally M Stein and J Lord, 'Monitoring The Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities, and Future Potential', *Human Rights Quarterly* 32(2) (2010): 689
- ¹⁵ CRPD, Article 35. See also United Nations Committee on the Rights of Persons with Disabilities, *Guidelines on Treaty-Specific Document to be Submitted by States Parties under Article 35(1) of the Convention on the Rights of Persons with Disabilities* (Geneva: UN, 2009).
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- ¹⁷ CRPD, Article 33. See further A Hoefmans and G de Beco, 'The UN Convention on the Rights of Persons with Disabilities: An Integral and Integrated Approach to the Implementation of Disability Rights' (Background document prepared for the international conference. 'Work Forum for the Implementation of the UN Convention on the Rights of Persons with Disabilities', Brussels (18-19 November 2010) available at http://www.socialsecurity.fgov.be/eu/docs/agenda/18-19_11_10_background_document.pdf (accessed July 18, 2013); G. De Beco, 'Article 33(2) of the UN Convention on the Rights of Persons with Disabilities: Another Role for National Human Rights Institutions?', *Netherlands Human Rights Law Quarterly* 4(1) (2011); Mental Disability Advocacy Center, *Building the Architecture for Change: Guidelines on Article 33 of the UN Convention on the Rights of Persons with Disabilities* (Budapest: MDAC, 2011); Office of the High Commissioner for Human Rights, *Thematic Study by the OHCHR on the Structure and Role of National Mechanisms for the Implementation and Monitoring of the CRPD. A/HRC/13/29*, 22 December 2009 available at <http://www2.ohchr.org/english/bodies/hrcouncil/docs/13session/A-HRC-13-29.pdf> (accessed July 21, 2013).
- ¹⁸ See CRPD, Articles 4(3) and 33(3) and, for further discussion, G Quinn, 'Resisting the "Temptation of Elegance": Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, ed. A Arnardóttir and G Quinn (Leiden: Martinus Nijhoff Publishers, 2009), 215-256; Mental Disability Advocacy Center, *Building the Architecture for Change: Guidelines on Article 33 of the UN Convention on the Rights of Persons with Disabilities* (Budapest: MDAC, 2011).
- ¹⁹ Mark Priestley is scientific director of the Academic Network of European Disability experts (ANED) and Anna Lawson is a member of its core research team. ANED has been funded 2008-2014 by the EU PROGRESS initiative to the value of €3.95m.
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- ²³ See the articles contained in A Mukherjee (ed), *International Journal of Human Rights: Special Issue on Torture Prevention and Disability*, 16(6)(2012).
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