Monitoring the Implementation of the UN Convention on the Rights of Persons with Disabilities in Europe: Principles for the Identification and Use of Indicators

Report prepared for the Academic Network of European Disability Experts (ANED)

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1. Introduction

The Academic Network of European Disability experts (ANED) was established by the European Commission in 2008 to provide scientific support and advice for its disability policy Unit. In particular, the activities of the Network support the future development of the EU Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).[1] Monitoring the extent to which disabled people are able to participate in the life of mainstream society is a challenge with which the European Commission has been increasingly concerned and with which the CRPD now requires all concluding States and regional international organisations (including the European Community) to grapple.

This report focuses on principles underlying the identification of indicators to be used in monitoring the implementation of the CRPD and provides examples of indicators already in use in the monitoring of disability rights. This report adopts a top-down approach and considers the kinds of indicators that will be required by the CRPD. It outlines examples of some monitoring methods already in use and aims to provide a first step in generating ideas about the type of indicators that might be appropriate for future development. A parallel report, also commissioned by ANED, provides a bottom-up review of existing statistical datasets from which quantitative comparisons might also drawn between the situations in different European countries.[2]

The examples used for illustration were gathered using a range of methods (including responses to a questionnaire and telephone interviews). The report has also drawn heavily upon information published on the websites of organisations active in the field of monitoring disability rights (including equality or human rights commissions and disability organisations). In addition, reference has been made to a number of academic publications (see Annex 1).

It is important to stress at the outset that the monitoring of disability rights is a highly topical issue, on which a great deal of work is currently being carried out – by disability organisations, by national governments and human rights institutes, by regional international organisations and also by the UN. At the UN level, for instance, the Human Rights Council has instructed the Office of the High Commissioner for Human Rights to conduct a thematic study on the issue.[3] An extensive set of preliminary indicators for the CRPD has recently been released by Queensland Advocacy Incorporated.[4] This report makes interesting reading and the indicator set it contains is reproduced in Annex 2 of this report. More such initiatives and works are likely to emerge over the next few months.

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[1] http://www.un.org/disabilities/

[2] The online questionnaire is available at http://www.surveymonkey.com/s.aspx?sm=zsnRRU6m0KQbev1HrWbB2Q_3d_3d

[3] 'Human Rights of Persons with Disabilities', resolution 7/9 of 4 June 2008. A consultation on this thematic study was held in Geneva on 24 October 2008 – see also, http://www2.ohchr.org/english/issues/disability/HRCResolution79.htm

[4] P. French, Human Rights Indicators for People with Disability: A *Resource forDisability Activists and Policy Makers* (Queensland, Queensland Advocacy Incorporated, 2008) available at http://www.hreoc.gov.au/disability_rights/convention/DC131207HumanRightsIndicatorsV2%20(2).zip

This report (based on 10 days funded work during 2008) aims only to provide an overview of the subject and an indication of current practice and thinking. In the Conclusion, some suggestions will be made as to directions for the next phase of development work in this area.

2. The Monitoring Provisions of the CRPD

The CRPD contains a number of provisions relating to monitoring. These have an important bearing on this report and need therefore to be set out in some detail.

Article 33(2), which represents a new departure for international human rights treaties, requires Parties to establish domestic frameworks or bodies (including independent mechanisms) to take responsibility for CRPD monitoring. Accordingly:

> States Parties shall … maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms as appropriate, to promote, protect and monitor implementation of the present Convention.

Under Article 35, each concluding Party must supply the Committee on the Rights of Persons with Disabilities with a ‘comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard’. The first report must be submitted within two years of the entry into force of the Convention in that country and subsequent reports must be supplied at four-yearly intervals thereafter.

In addition, Article 31 requires Parties to ‘collect appropriate information, including statistical and research data, to enable them to formulate and implement policies’ giving effect to the Convention. It specifies that such information should be used to ‘help assess the implementation of States Parties’ obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights’. This provision provides a clear indication of the need for evidence based policy-making, based on robust research data.

The challenge of making connections between the requirements of Articles 31, 33(2) and 35 should not be overlooked. Monitoring bodies will require guidance on appropriate indicators, and access to robust data. Such approaches should also be consistent with the requirements of state reporting mechanisms. This joined-up practice will not be easily achieved and it will be important to establish dialogue between the European Communiy relevant state parties and the research community.

3. Principles Underlying the Identification of Monitoring Indicators for CRPD Rights

3.1 Involvement

Fundamental to the CRPD is the notion that disabled people should be fully involved in all aspects of its implementation. This is unsurprising given the significant role played by disabled people's organisations in the elaboration of the Convention and their adherence to the motto 'Nothing about us without us'. Accordingly, Article 4(3) of the Convention provides that:

> In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

In addition, 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.

The full involvement of disabled people in the development of monitoring systems (including the selection and evaluation of indicators) can therefore be viewed as mandatory. It is also likely to enhance the effectiveness of any monitoring system – a point also stressed by international disability monitoring projects such as the International Disability Rights Monitor[5] and Disability Rights Promotion International[6].

The Irish National Disability Authority, in its helpful discussion of monitoring disability equality[7], identified two principal approaches that might be adopted when consulting disabled people on the selection of indicators. The first (which it termed 'advance consultation') involved asking key stakeholders to identify issues or areas of life which they considered particularly significant. Indicators would then be formulated to correspond to the identified issues or topics[8]. The second (which it termed 'consult on basis of provisional list') involved formulating an initial set of indicators (drawing upon those which might be used internationally) and asking key stakeholders for feedback upon them.

There is clearly room for both these consultative approaches. Given that the Convention itself represents an identification of priority issues and areas of life, and that its implementation in all those areas is mandatory, the second approach would appear to have more relevance to the current issue. The research community is well placed to play a useful role in helping to identify potential indicators and sources of comparative data.

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[5] http://www.ideanet.org/uploads/Flash/IDRM_map_06.swf .

[6] www.yorku.ca/drpi .

[7] *How Far Towards Equality? Measuring how Equally People with Disabilities are Included in Irish Society* (Dublin, NDA, 2005) ch 9.

[8] For an example of the use of this technique in the context of children's well-being, see S Hanafin, A-M Brooks, E Carroll, E Fitzgerald, S Gabhainn and J Sixsmith, 'Achieving Consensus in Developing a National Set of Child Well-Being Indicators' (2007) 80 *Social Indicators Research* 79.

Any draft set of indicators prepared by the Commission should be developed in conjunction with, and finalised only after full and meaningful consultation with, relevant disability organisations (such as the European Disability Forum).

3.2 Comparability

3.2.1 Comparisons over Time

Monitoring implementation of the CRPD serves a number of purposes. Foremost amongst these is the provision of information about the progress being made by individual States towards the full realisation of Convention rights. This requires comparisons to be made between levels of implementation within a country over time. Such comparisons can be made only if monitoring is carried out on an on-going basis. As Disability Rights Promotion International (DRPI) recently put it, effective disability rights monitoring 'is not a snapshot but an on-going video'[9]. In order to achieve this longitudinal comparison it is necessary to establish baseline measurements of the current situation. This presents some significant challenges but suggests that immediate work is required to begin developing indicators and identifying relevant data sources (including the collection of new data where required).

3.2.2 Comparisons between Disabled and Non-Disabled People

Effective monitoring of equality will require comparisons to be drawn between the position of disabled people and their non-disabled peers. The primary aim of the CRPD is, after all, to ensure that disabled people are able to enjoy their human rights on an equal basis with others. Such comparative information can best be obtained through the use of mainstream or generic data collection directed at the general population (i.e. where disabled people are identified by relevant variables in the survey design).

The potential power of generic studies as a means of monitoring disability rights was recognised by Bengt Lindqvist during his tenure as Special Rapporteur. In his words:

> The principles of full participation and inclusion, which are the dominant ideas in modern disability policy, strongly favour building effective monitoring of the human rights of persons with disabilities as an integral part of existing monitoring mechanisms[10].

As the scoping conducted by ANED in 2008 shows, reliance on generic studies alone, however, is unlikely to provide sufficient information as to the nature and extent of all the barriers facing disabled people. It is therefore likely to be necessary to conduct disability-specific monitoring exercises, or targeted disability surveys, in addition to generic studies.

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[9] *Moving Forward: Progress in Global Disability Rights Monitoring*, (Toronto, DRPI, 2007) – available at www.yorku.ca/drpi .

[10] Report of the Special Rapporteur of the UN Commission for Social Development on monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities on his third mandate, 2000-2002, available at http://www.un.org/esa/socdev/enable/disecn520024e0.htm

3.2.3 Comparisons between Countries

Internationally, and within Europe, effective monitoring mechanisms should allow for comparisons to be drawn between the levels of implementation in different countries. The importance of this was recognised at the UN International Seminar on Measurement of Disability in New York, June 2001[11].

As a result, the Washington City Group on Disability Measurement[12] was established and charged with the task of developing methodologies and indicators for monitoring disability issues and thereby facilitating the making of country comparisons.

This type of exercise presents considerable challenges, given the varying availability of national data in different policy domains and the use of varied disability definitions in national data collection. However, the European Union is perhaps better placed, better resourced and more experienced than other regions to structure and collate such comparative data. Conclusion of the Convention by the EC would point towards a key role for European institutions (including Eurostat) in defining, collecting and reporting data under Articles 31 and 35.

3.3 Definition and Measurement (Disabled People)

Crucial to the making of meaningful comparisons is the use of indicators that are consistently demonstrable and/or measurable. This presents very significant challenges. One of the principal difficulties in measuring outcomes for disabled people is the identification of those people to be classified as 'disabled'. Clearly, the way in which disabled people are identified has significant implications for measurements of, for example, the percentage of disabled people who attend mainstream school, who graduate from university or who secure particular types of employment, etc.

The CRPD does not provide an exhaustive definition of a 'person with a disability' but does indicate, in Article 1, that:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

This raises interesting questions about the relationship between the CRPD approach and national definitions, such as that contained in section 1 of the UK's Disability Discrimination Act 1995. Under the latter, a person must have a physical or mental impairment which has a 'substantial' and 'long-term' adverse effect on their ability to carry out 'normal day-to-day activities – a definition broadly equivalent to that which was enunciated by the European Court of Justice in the case of Chacón *Navas v Eurest Colectividades*[13] in the context of the EC Employment Equality Directive[14].

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[11] http://unstats.un.org/unsd/disability/Seminar%202001.html

[12] http://www.cdc.gov/nchs/citygroup.htm

[13] Case C-13/05 *Chacón Navas v Eurest Colectividades SA*, [2006] ECR I-6467.

[14] Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation (Official Journal L 303, 2 December 2000 P 16).

If the interpretation of 'person with disability' is broader than the domestic interpretation (e.g. because it does not require an impairment to be 'substantial') some States (and regional international organsiations) may need to broaden their own interpretation for monitoring purposes. Failure to do so would have the obvious consequence of monitoring implementation of the CRPD in relation to only some of those whose rights it is intended to protect. How extensively the term 'persons with disabilities' will be interpreted by the Committee on the Rights of Persons with Disabilities, however, remains to be seen.

There is currently no international agreement on the definition of a 'disabled person' or on the use of terminology. Thus, the CRPD (in its English translation) uses the terminology of 'persons with disabilities'. Adherents to the social model (in the UK), however, generally refer to 'people with impairments' and reserve the term 'disability' for the exclusionary effect that socially created barriers imposes on this group[15]. Thus, on this view, a disabled person would be a person with an impairment who is disabled by the operation of societal barriers but not a person with an impairment who lives in an ideal society in which all disabling barriers have been removed.

The social model debate raises a significant conceptual question about the measurement of progress on outcomes. This might be exemplified in the kind of questions often employed in national surveys such as the Labour Force Survey (i.e. where it is possible for respondents to report having an impairment but to deny that this would 'substantially limit your ability to carry out normal-day-to-day activities'.). If barriers were successfully removed and participation levels increased then one might anticipate that, while the number of 'people with impairments' would remain stable, the number of 'disabled people' would decline.

The terminology of the Convention, as regards the social model debate, is somewhat equivocal – a point which is discussed in some depth in a helpful article by Kayess and French.[16] Nevertheless, it seems clear that the key purpose of monitoring its implementation will be to gather information as to the extent to which people with impairments are able to participate in society and to access human rights on an equal basis with others. It seems likely, therefore, that ascertaining the class of people with impairments (independent of the impact of the impact of disabling barriers upon them) will prove an essential element of effective CRPD monitoring. Without such information, monitoring any progress made in the removal of relevant barriers in the way of the enjoyment of rights (including attitudinal barriers and those taking the form of inadequate support, such as failures to make provision for mobility aids or for supported decision-making) would become extremely difficult.

Even if there were international agreement on the definition of a person with an impairment or a disability, the problem of inconsistent self-reporting would remain. Research indicates that the incidence of self-reporting is sensitive to the way in which questions are phrased. The number of people claiming to have a 'chronic' illness or disability, for instance, may be quite different from the number of people claiming to have one which is 'long-standing'[17].

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[15] See eg M Oliver, *The Politics of Disablement* (Basingstoke, Macmillan, 1990); M Oliver, *Understanding Disability: From Theory to Practice* (Basingstoke, Macmillan, 1996); C Barnes and G Mercer, *Disability* (Malden, Polity Press, 2003); M Priestley, 'Constructions and Creations: Idealism, Materialism and Disability Theory' (1998) 13 *Disability and Society* 75; V Finkelstein, 'Representing Disability' in J Swain, S French, C Barnes and C Thomas (eds), *Disabling Barriers—Enabling Environments* (London, Sage, 2004).

[16] R Kayess and P French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 *Human Rights Law Review* 1.

[17] B Gannon and B Nolan, *Disability and Labour Market Participation* (Dublin, Equality Authority, 2004) 31.

Further, even where identical phraseology is used, the incidence of self-reporting is likely to vary between countries. Thus, the European Community Household Panel 1998[18] found that, while the incidence of self-reporting amongst 25-34 year olds in Italy was only 4.3%, the figure was as high as 27.7% in Sweden. In addition, there may be reluctance among many people with rights under the Convention to describe themselves as 'disabled', leading to significant under-reporting[19].

This may be particularly problematic in the context of 'mental health' where stigma appears to be especially high[20]. However, if stigma associated with disability reduces, then the number of people who report themselves as having an impairment or a disability is likely to increase – a phenomenon which appears to provide one explanation for the increase in the number of people describing themselves as disabled in the 2006 Canadian Participation and Activity Limitation Survey as compared with the number who did so in the 2001 survey.[21]

Such difficulties are likely to remain regardless of the language used. The most consistent approach to identifying impairment by self-reporting is likely to involve standardised questions concerning a person's physical, sensory, cognitive or psycho-social experience. The short list of questions recommended by the Washington City Group for inclusion in population censuses provides the most obvious example. The short list of 'Revised Census Questions on Disability Endorsed by that Group reads as follows (in each case the response options are defined as: No - no difficulty; Yes – some difficulty; Yes – a lot of difficulty; Cannot do at all).

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

The Group is currently working on extending this set, which has some obvious limitations (e.g. in relation to psycho-social conditions and physical impairments that do not affect walking, personal care or communication). Similar questions are used to identify disabled people in the five-yearly Canadian Participation and Activity Limitation Survey.[22]

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[19] See eg I Grewal, S McManus, S Arthur and R Leith, *Making the transition - addressing barriers in services for disabled people* (Department for Work and Pensions, London, 2004) where only 48% of those classified as 'disabled' for purposes of the study were willing to report that they had a 'disability'; and S Dex and K Purdam, *Implementing equal opportunities (*Joseph Rowntree Foundation, York, 2005)

[20] S Rooke-Mathews and V Lindow, *The Experiences of mental health service users as Mental Health Professionals. Findings 488* (York, Joseph Rowntree, 1998).

[21] http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3251&lang=en&db=imdb&dbg=f&adm=8&dis=2

[22] http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3251&lang=en&db=imdb&dbg=f&adm=8&dis=2

Questions such as those recommended by the Washington Group, however, are not unproblematic. In referring to the difficulty associated with the performance of certain tasks (such as dressing, washing and communicating) they fail to differentiate between the functional limitations of an impairment and the disabling consequences of inadequate support. Thus, a person with a physical impairment may have difficulty in dressing or washing if unassisted. If provided with adequate support (in the form of assistive devices or of personal assistance), however, the difficulty might well be removed. It is therefore unclear whether these questions are attempting to measure the level of a person's functional limitation or the adequacy of social responses to that limitation.

3.4 Definition and Measurement (Disabling Barriers)

In parallel with the identification of people with impairments (or disabilities), indicators of progress on implementation of the Convention must clearly involve some measurement of disabling barriers. Such an approach, indeed, is not only required by the CRPD but is also fundamental to the adoption of a social model of disability by the European Union.

Until relatively recently, the assessment of disabling barriers was absent from the vast majority of disability monitoring systems – a point which attracted criticism from disability activists and which sat uncomfortably with a social model approach to disability[23]. The importance of measuring the impact of social and environmental barriers on disabled people's lives was recognised by the World Health Organisation when, in 2001, it adopted environmental classifications within the International Classification of Functioning, Disability and Health (ICF)[24].

The European Disability Action Plan priority on 'accessibility' (in goods, services and infrastructures) provides a helpful reference point here in clarifying what is required. In this context, it is possible to conceive of a wide range of potential indicators of accessibility that could be considered. For example, such indicators might include the proportion of wheelchair accessible buses or railway stations in a country, the proportion of television programmes which are subtitled or audio-described, the proportion of government web sites designed in accordance with accessibility standards, and so on.

However, there are two major difficulties in developing this kind of approach. First, the relevant data to support measurement and comparisons may not be readily available in existing public datasets. Second, certain groups of disabled people are likely to be privileged in the definition of more easily measurable accessibility criteria (e.g. the social barriers facing people with psycho-social conditions and intellectual impairments may appear more difficult to measure in tangible ways). It is relevant to note, however, that measurements of public opinions and attitudes should be included within the frame of measuring disabling barriers. The ANED mapping report on comparative statistical data sources identifies such shortcomings in European datasets. This is clearly an area in which new approaches to measurement and new indicators need to be developed as a matter of urgency.

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[23] See eg P Abberley, 'Counting us Out: A Discussion of the OPCS Disability Surveys' (1992) 7 *Disability, Handicap and Society* 139.

[24] 54th World Health Assembly, resolution WHA 54.21; available at http://www.who.int/classifications/icf/en/

3.5 Intersectionality

The class of 'disabled people' includes people with all types of impairment as well as people of all ages, genders, sexual orientations, religions and ethnic origins. The rights protected by the CRPD apply to all and it is essential that monitoring processes are designed and implemented in a manner that captures such differences and intersectionality.

Care must therefore be taken to ensure that specific groups of disabled people are not excluded from involvement in, or neglected in the coverage of, monitoring exercises. Particular care needs to be taken to ensure that specific groups are included in monitoring exercises and that indicators are designed so as to allow information relating to them to be disaggregated.

Many mainstream monitoring exercises (and disability-specific surveys) have traditionally been directed selectively at people living in private households[25] or at people of working age[26].

Purdam et al[27] have recently drawn attention to the insensitivity of current UK information on disability. They observe that:

> For certain groups (including children) there aren't even agreed estimates of the numbers of disabled people. There is no specific survey designed to capture the circumstances of disabled children and young people and few of the national surveys capture this information effectively. This is a major gap in the evidence base for monitoring equality and hinders effective evidence-based policy development and service provision.[28]

They also observe that:

> There is no current reliable comprehensive measure of disabled people's economic circumstances apart from those of working age and no reliable estimates exist of the number of disabled people from minority ethnic populations by detailed ethnic categories.[29]

The need to ensure that data can be used to identify particular levels of disadvantage or exclusion which may affect specific groups of disabled people is reflected in the Convention. Article 31, which imposes an obligation on Parties to collect relevant data, accordingly specifies that:

> (2) The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

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[25] See eg the British Household Panel Survey, available at http://www.iser.essex.ac.uk/ulsc/bhps/

[26] See eg the British Labour Force Survey, available at http://www.statistics.gov.uk/STATBASE/Source.asp?More=Y&vlnk=358#general

[27] K Purdam, R Afkhani, W Olsen and P Thornton, 'Disability in the UK: Measuring Equality' (2008) 23 *Disability and Society* 53.

[28] Ibid, p 60

[29] Ibid, p 61

Parties would therefore be wise to ensure that data is collected in such a way as to allow the situation of particular groups of disabled people (e.g. those who have a particular impairment, those who are women and those who may be particularly vulnerable to multiple forms of oppression or disadvantage) to be extracted and examined. Some guidance as to the types of group that might be relevant for these purposes may be derived from paragraph p of the preamble. According to this, Parties are:

> Concerned about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.

This form of disaggregation may require significant revision of traditional data collection methods and indicators.

3.6 Dissemination

Article 31(1), as noted earlier, imposes an obligation on Parties to 'collect appropriate information, including statistical and research data'. Article 31(3) asserts that:

> States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Although only 'statistics' are specifically mentioned here, Parties would be wise to interpret the provision broadly as applying also to 'research data' and other types of 'appropriate information' collected in pursuance of Article 31(1). Thus, dissemination and accessibility of such information should therefore include both quantitative and qualitative indicators of progress towards full enjoyment of disabled people's rights.

The importance of effective dissemination cannot be overstated. Making relevant monitoring information available to legislators and policy-makers is a necessary pre-condition for the development, evaluation and refinement of effective evidence-based policies. Making it available to disabled people, their organisations and other relevant bodies is a necessary pre-condition of effective lobbying and strategy development. It is, in addition, an essential element of the meaningful 'involvement' of disabled people, not only in the monitoring process, but also in the process of policy development. The importance of the latter is reiterated in paragraph o of the Preamble, which affirms that disabled people 'should have the opportunity to become actively involved in decision-making processes about policies and programmes, including those directly concerning them'.

It is worth noting that data collection tools can themselves perform a dissemination function (i.e. in raising awareness of strategic expectations, stimulating debate and highlighting options for intervention). For example, the stated objectives of The Global Survey on Government Action on the Implementation of the Standard Rules for the Equalization of Opportunities for Persons with Disabilities (discussed in the next section) were, not simply to monitor implementation but also to raise awareness of their requirements.

Thus Paragraph 12 of the report lists amongst the purposes of the study:

b. Increase Governments' awareness of the Standard Rules and draw their attention to their moral and political obligation to implement them;
c. Present to Governments possible steps to implement the Standard Rules by listing them among the responses to each question;
j. Use the survey as a tool to encourage dialogue at the national and regional levels between disabled persons' organizations and Governments around the issues of equalization of opportunities. The survey may also serve as a guide to Government interventions.

In order to achieve effective dissemination it would be helpful to structure the presentation of indicator information for each country in a way that highlights key messages and headlines that can be compared with other countries. It will also be important to make such information easily and publicly accessible in a standard form available from a single location (e.g. via a website). Whilst the totality of data and measures will be complex, requiring detailed knowledge of analytical limitations, it would be useful to develop a simplified 'scorecard' tool to present key messages and comparisons.

This could be achieved by selecting a short list of key areas (probably not more than 20), in consultation with disabled people's organisations, and scoring each according to the extent to which associated CRPD rights. This will require performance to be measured against a range of defined targets. The pace of progress might be demonstrated by, for example, the use of a green-amber-red 'traffic light' mark. Similar methodologies have been increasingly used to monitor progress on institutional strategy in large commercial and public sector organisations. Most notably, this has involved various adaptations of a Balanced Scorecard method[30].

In the context of disability rights, the International Disability Rights Monitor Project (discussed in section 4 below) has used a 'report card' system in its methodology. In 2007, the UK Equalities Review[31] recommended the use of an 'equality scorecard' system to monitor progress on all forms of equality, including disability equality. The scorecard it recommended would monitor equality in ten key dimensions or areas of life. These were arrived at after consultation and a review of human rights literature. They read as follows:

- longevity, including avoiding premature mortality
- physical security, including freedom from violence and physical and sexual abuse
- health, including both wellbeing and access to high quality healthcare
- education, including both being able to be creative, to acquire skills and qualifications and having access to training and life-long learning
- standard of living, including being able to live with independence and security; and covering nutrition, clothing, housing, warmth, utilities, social services and transport
- productive and valued activities, such as access to employment, a positive experience in the workplace, work/life balance, and being able to care for others
- individual, family and social life, including self-development, having independence and equality in relationships and marriage

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[30] See eg R Kaplan and P Norton, *'The Balanced Scorecard'* (1996) ???
[31] *Fairness and Freedom: The Final Report of* the *Equalities Review*, (London, Stationery Office, 2007,) available at http://www.theequalitiesreview.org.uk/upload/assets/www.theequalitiesreview.org.uk/equality_review.pdf .

- participation, influence and voice, including participation in decision-making and democratic life
- identity, expression and self-respect, including freedom of belief and religion
- legal security, including equality and non-discrimination before the law and equal treatment within the criminal justice system.[32]

It is important to add that any high-level strategy management and dissemination tool would need to be supplemented by more in-depth reporting. It would require substantial work in the development of its underlying evidence/target/data definitions.

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[32] Ibid, ch 1.

4. Examples of Monitoring Strategies and Associated Indicator Sets

The purpose of this Section is to highlight some examples of different monitoring strategies and indicators used or developed by a range of different organisations. Only disability-specific monitoring strategies will be considered here (the ANED mapping report on comparative European data sources provides extensive examples of a range of generic data types and their limitations).

4.1 The Global Survey on Government Action on the Implementation of the Standard Rules for the Equalization of Opportunities for Persons with Disabilities[33]

This monitoring study was conducted by the Special Rapporteur on Disability in 2004-5. It focused on responses to questionnaires sent to the Governments of all 191 countries which had adopted the Standard Rules. Questionnaires were also sent to two disability organisations in each of those countries.

The questionnaire contained detailed questions relating to the measures taken by governments to implement each of the Standard Rules. The indicators thus took the form of criterion-referenced judgements on the adoption of specified legal or policy measures, rather than the measurement of disabled people's participation or of disabling barriers. According to the report of the Special Rapporteur[34]:

> The survey is a comprehensive, detailed document, inclusive of every procedure Governments have agreed to implement in fulfilment of their commitment to the equalization of opportunities. Each question included a checklist relating to the procedure, and respondents were requested to tick applicable responses.

Examples of the responses obtained are helpful in considering the nature of the indicators and their relevance to the monitoring required by the CRPD. The Report's summary of findings relating to Rules 1 and 2 are therefore reproduced overleaf for purposes of illustration.

It is clear from these extracts that the reporting focus is on the adoption of a law or other measure rather than the extent, quality or impact of its practical implementation. The content of such laws or policies is not explained in detail – unlike, for instance, in the reports of the EU Network of Legal Experts on Non-Discrimination Law.[35] Neither, at least within the summary findings, is it evident what role disability organisations played in assessing the effectiveness of the relevant laws or policies. The usefulness of this type of monitoring strategy in the context of the CRPD is therefore limited. Nevertheless, qualitative indicators which are framed around the existence or adoption of specific measures, policies or laws clearly have an important role to play in any CRPD monitoring system.

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[33] Set out in the Report of the Special Rapporteur on Disability of the Commission for Social Development - Monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities [E/CN.5/2005/5] - Part 1) available at http://www.un.org/disabilities/default.asp?id=53#2. See also Report of the Special Rapporteur on Disability of the Commission for Social Development, E/CN.5/2005/5, 30 November 2004.

[34] Ibid.

[35] http://ec.europa.eu/employment_social/fundamental_rights/policy/aneval/legnet_en.htm

Care should be taken, however, to ensure that they are complimented by other types of indicator that disclose more information about the effectiveness of the intervention in question.

Rule 1
Awareness-raising

25. Respondents were asked about the measures taken to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.
26. Some 64.0 per cent of respondents stated that their countries had adopted national awareness-raising policies, while 58.8 per cent responded that they had passed legislation.
27. Concerning the adoption of programmes and the drafting of media guidelines for raising public awareness, 61.4 per cent and 30.7 per cent, respectively, responded that they had done so. Additionally, 52.6 per cent of the responding countries said they had trained personnel in raising public awareness; 58.8 per cent had disseminated printed materials; 37.7 per cent had integrated awareness-raising into the school curriculum; and 53.5 per cent had worked on educating the public about the rights, needs and potential of persons with disabilities. The survey also revealed that 75.4 per cent of countries that responded routinely consult and collaborate with organizations of persons with disabilities.
28. Many countries also provided examples of the measures taken to raise public awareness, such as designating a national day and celebrating the International Day of Disabled Persons (3 December).
29. In response to the question about the nature and scope of the awareness-raising materials, 67.5 per cent stated that they covered all types of disabilities, including developmental and psychosocial disabilities; 70.2 per cent indicated that materials were inclusive of the social, political and development rights of persons with disabilities; and 69.3 per cent responded that the materials included the right to services, full participation and equal opportunities.
30. On the issue of the potential of persons with disabilities, 64.9 per cent responded that their materials raised awareness of the issue; 66.7 per cent indicated that their materials included contributions of persons with disabilities to social, cultural, scientific and economic spheres; and 67.5 per cent responded that their media content described persons with disabilities in positive terms, considered the rights of persons with disabilities, and gave ample weight to issues of rights, diversity, dignity and equality.
31. In 15.8 per cent of responding countries, the media promote attitudes of pity and compassion or negative stereotypes, in addition to discounting the role, needs and even the existence of persons with disabilities.

Rule 2
Medical care

32. Respondents were asked whether Governments provided effective medical care to persons with disabilities.
33. Of the countries that responded to the survey, 60.5 per cent indicated they had adopted policies to ensure access to effective medical care for persons with disabilities; 44.7 per cent had passed legislation; 56.1 per cent had introduced programmes; 64.9 per cent had allocated funds for medical care; and 56.1 per cent had trained medical personnel to deliver appropriate medical programmes.
34. Additionally, 64.9 per cent indicated that they had made medical care accessible to persons with disabilities. The proportion of countries that consulted with disabled persons' organizations was 60.5 per cent, and 56.1 per cent of responding countries stated that they provided persons with disabilities with accessible information on medical services.
35. Many countries also indicated other measures, such as setting up occupational rehabilitation units.
36. In response to the question about measures relating to the health of persons with disabilities, 71.1 per cent stated that they had taken steps to raise awareness about the causes of disability; 78.1 per cent had worked on improving pre- and postnatal care; 65.8 per cent had implemented early detection; and 64.9 per cent had implemented early intervention measures.

4.2 The International Disability Rights Monitor Project (IDRM)[36]

The IDRM was founded in 2003 in response to a perceived lack of information about the circumstances of disabled people. Its aim is 'to promote the full inclusion and participation of people with disabilities in society and to advance the use of international humanitarian law in ensuring that the rights of people with disabilities are respected and enforced'.

The IDRM has published a number of reports on the circumstances of disabled people and the extent to which they are able to participate in various aspects of the life of mainstream society. These reports represent attempts to document the extent to which human rights protection is afforded to disabled people in practice. The geographical regions which have been covered by the reports published to date are the Americas, Asia and Europe. These reports, which include specific sections on individual countries, may be downloaded from the IDRM website.[37]

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[36] http://www.ideanet.org/content.cfm?id=5F5A&memberMenuid=0
[37] http://www.idrmnet.org/content.cfm?id=5E5A77&m=1&CFID=34782&CFTOKEN=85148220

The methodology used by the IDRM is explained in the following terms in its recent report on Europe:

> The methodology employed in IDRM research is primarily of an exploratory nature, with the guiding question being, “what rights and conditions are experienced by persons with disability in each country?” The items contained in the research guide include closed-ended (yes/no) questions and open-ended questions for data collection. This methodology consciously combines a quantitative approach, eliciting data that is comparable across countries, and a qualitative approach to obtain textured responses that will support a narrative description of the situation in each country. Researchers are not limited to questions included in the guide but rather are encouraged to document situations and circumstances in their locale.
>
> Items in the research guide were largely designed with the recommendations of the Standard Rules in mind. The questions were then refined via consultation with members of the international disability community and experts on disability law in a variety of jurisdictions. Once the IDRM project was officially underway, the questions were again evaluated by international disability experts as well as by disability advocates, including IDRM local researchers. The research guide (also known as the questionnaire) is comprised of 107 distinct questions. A total of 91 items were included in the main body of the guide. Sixteen items were included in the panel discussion section. Of these, three were also included in the main body.
>
> The questions in the main body of the research guide were distributed among four sections focusing on different topic areas. Ten items were concerned with identifying the population of people with disabilities in the country. To accomplish this, the researchers obtained statistical materials and interviewed national governmental officials to gauge the accuracy of the existing data.
>
> The second section of the research guide, entitled “Disability Rights,” is comprised of 24 items, with several questions asking researchers to follow up certain responses with further questions. This section deals primarily with the nature of national laws and policies protecting the rights of persons with disabilities, including anti-discrimination laws, and protections of civil, political and social rights. It also addresses questions on the institutionalization of persons with disabilities.
>
> The third section of the guide addresses issues of inclusion and accessibility. This part is divided into six segments, comprising a total of 43 items. The segments include: communication, education, employment, health services, housing, and accessibility of the built environment.
>
> The fourth section addresses the activities of disability organizations at the national and local levels. This section includes items related to governmental entities as well as non-governmental entities. It was comprised of eight items. In order to complete these questions, researchers collected epidemiologic and census data as well as materials related to laws and statutes regarding disability.

Researchers also conducted interviews with a variety of officials and disability leaders to obtain additional information and verification of policies. Researchers selected interviewees based on their positions within governmental ministries and agencies, and for their reputation as having expertise in the issue area. In addition, the researchers gathered attitudinal/opinion data from focus groups comprised of disability leaders. The methodology for the panel sessions differed from the methodology used to obtain responses and data for the main questionnaire items. Focus panels are conducted with experts on disability—persons with personal experience of disability and/or long-standing work in the field of disability.

The researchers then conducted an open-ended discussion around the 17 panel questions. Panel session results generally do not produce data that can be easily analyzed, statistically or otherwise.
Instead, panel sessions produce a great deal of verbal data, which must be summarized before justifiable conclusions can be drawn. The purpose of these panel discussions was to gain understanding and insight into the issues of disability in the countries in question, not to quantify an opinion of a larger population.

IDRM researchers are generally based in the country in question and active members of its disability community. They are trained in data collection methodology before embarking on the research required in their own countries. They consult with both government officials and civil society leaders in preparing their reports.

The IDRM country reports are generally fairly lengthy and detailed. In order to facilitate the drawing of cross-country comparisons, IDRM has compiled 'report cards' for each country. These disclose the performance of that country against ten specific indicators. Based on this performance, each country is categorised as 'most inclusive', 'moderately inclusive' or 'least inclusive'. The report card indicators are as follows:

IDRM Regional Report of Europe 2007 Report Card Questions

Convention/Optional Protocol Signing

Q. Has your government signed the Convention on the Rights of Persons with Disabilities and Optional Protocol?

Legal Protection

Q. Is there a national law that specifically references and protects of the rights of people with disabilities?

Education & Employment

Q. Is training on teaching children with disabilities included in the curriculum used for all teachers in your country?

Q. What is the largest employer in the private sector? Do they have a policy that states people with disabilities cannot be discriminated against in employment on the basis of his or her disability?

Accessibility

Q. Is the public transport system in the capital city accessible?

Health Services & Housing

Q. Is physician training on provision of care to people with disabilities available during both medical school and residency?

Q. Is there a center that provides peer counselling and referral services concerning housing (Independent Living Center) to people with disabilities in your country? Who operates these services?

Communication

Q. Is your prime ministers website WAII compliant (website/caption news)?

Whilst there are some obvious limitations in this selective format, and alternative key questions could be substituted, there is some merit in such an approach for summary headline dissemination. Improvements could be made in constructing a report tool for the EU context linked to priorities in EU strategy and closed (yes/no) questions could be substituted with indicators of progress against defined targets.

The report card certainly provides a convenient and easily accessible indicator set on which to base comparisons. However, as the IDRM Europe report acknowledges, it does not currently give sufficient profile to certain types of right (e.g. political rights). Further, the indicators selected could be easily manipulated by countries keen to appear to have made progress if there were an expectation that the same report card would be used in future monitoring exercises. While its brevity has some appeal, the use of equality dimensions (performance in which is measured by reference to a longer and more complex set of indicators - along the lines suggested by the Equalities Review and explained above), would seem to provide a more reliable guide to the level of CRPD implementation in different countries.

The IDRM reports provide a valuable source of information about the extent of human rights protection afforded to disabled people and it is likely that future reports will be more closely tailored to the CRPD. Unlike the Global Survey on the Implementation of the Standard Rules, the IDRM does not depend on self-reporting by governments. It establishes an independent mechanism, which involves disabled people, for monitoring the adoption of legal and policy measures.

It also provides space for evaluations of the effectiveness of such laws and policies. If applying such an approach to formal EU monitoring it would be relevant to consider carefully the selection and training of evaluators.

The IDRM Europe report acknowledges that IDRM researchers are dependent on existing published data on, for instance, participation levels of disabled people in education systems or employment and that the shortage of such information is a major constraint on its work. There would be scope for the EU to improve on this constraint by actively shaping the way that data is collected and reported in support of its own monitoring functions.

4.3 Disability Rights Promotion International (DRPI)[38]

The DRPI project was established with the aim of developing a comprehensive and sustainable system for monitoring the human rights of disabled people throughout the globe. It was established in response to the recommendations of the Almåsa Seminar, held in 2000 and hosted by Bengt Lindqvist (who was then the UN Special Rapporteur on Disability).[39]

DRPI has divided its work into three phases. The first phase, which was completed in December 2003,consisted of an investigation into the ways in which international human rights instruments might be used to enforce disability rights; the types of monitoring tools used by human rights monitoring projects; and the resources available for training human rights monitors and for promoting general education on human rights.[40] The second phase, which is not yet complete, consists of the development and testing of a range of tools, methodologies and training systems for the monitoring of disability rights. In Phase Three it is planned to use these instruments and tools to expand capacity-building, training and monitoring activities in many countries.

The DRPI asserts that five important principles underlie its work in all three of its phases. It describes these as follows[41]:

1. Involvement of people with disabilities and organizations of people with disabilities in the DRPI project itself and in all disability rights monitoring activities. DRPI recognizes that disability rights monitoring belongs to people with disabilities.
2. Emphasis placed on working with people with disabilities and disability organizations to build capacity to use the tools developed in the project to conduct disability rights monitoring, analyze the data collected and use the data to advocate for positive change. All monitoring tools and training resources developed by the project will be accessible, easy to use and freely available to all.
3. Recognition of the need for cross-disability involvement in monitoring activities, that is, people with a spectrum of disabilities both participate in monitoring and have their personal experiences monitored.

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[38] www.yorku.ca/drpi .

[39] Let the World Know: Report of a Seminar on Human Rights and Disability available at http://www.un.org/esa/socdev/enable/stockholmnov2000.htm .

[40] DRPI, Phase I Report: Opportunities, Methodologies, and Training Resources for Disability Rights Monitoring (York University Toronto, DRPI, 2003).

[41] DRPI, Moving Forward: Progress in Global Disability Rights Monitoring (York University Toronto, DRPI, 2007), ch 1.

4. Use of a holistic approach to monitoring in order to fully understand the human rights situation of people with disabilities, that is, analyzing data from all three focus areas (systems, individual experiences and media) to provide a comprehensive picture.
5. Engagement of individuals and organizations already involved in human rights monitoring as partners in the development of methodology and as a means of benefiting from past experience and ensuring the sustainability of disability rights monitoring efforts after the life of this project.

The fourth of these principles perhaps needs further explanation. In its 2007 'Moving Forward' report, DRPI elaborates further on what it means by a holistic approach to monitoring as follows[42]:

> A holistic approach involves monitoring in three focus areas:
> - monitoring systems (assessing the effectiveness of laws, policies, programs and case law in protecting and promoting the rights of people with disabilities);
> - monitoring individual experiences (gathering information about the actual human rights situation of people with disabilities on the ground); and
> - monitoring media (examining both the coverage and depiction of people with disabilities in the media).

In relation to its 'system's focus, the DRPI has developed links with Law Schools in different countries. It has also established links with Interrights, a mainstream human rights organisation, which is now looking to support strategic litigation in the area of disability rights. In addition, IDRM has developed a template to help with the collection of information about a country's disability-related legislation, policies and programmes. This template is intended to cover all types of right and to provide assistance both with the gathering of data and also with the identification of gaps in protection.

This template is not yet available from the DRPI website as it will not be finalised until its usefulness in a number of pilot studies has been assessed. One of these pilot studies – State of Disabled People's Rights in Kenya[43] - has now been concluded and its findings published. It suggests that the general methodology, including the template, worked surprisingly well given that it was a pilot study.[44]

Finally, in relation to the 'systems' focus, DRPI has worked with the Asia Pacific Forum of National Human Rights Institutions to develop a tool for tracking disability-related cases decided by national human rights institutions. Again, this is not yet available on the DRPI website.

DRPI's monitoring under its 'personal experience' focus is based upon the responses of disabled people during interviews conducted by trained monitors who must themselves be disabled and live (or have lived)in the geographical area in which the study is being conducted.

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[42] DRPI, *Moving Forward: Progress in Global Disability Rights Monitoring* (York University Toronto, DRPI, 2007), Executive Summary.

[43] African Union of the Blind and Centre for Disability Rights Education and Advocacy, State of Disabled People's Rights in Kenya (York University Toronto, DRPI, December 2007).

[44] Ibid, Appendix A.

It has developed a guide to the structure and conduct of these interviews which is set out in Annex 3 to this report. It should be stressed that this guide may well be changed in light of experience in the pilot studies which have not yet been completed.

The guide suggests that interviews are likely to be relatively non-prescriptive in terms of content, giving interviewees the freedom to identify and discuss rights issues of particular significance to them. The Kenya study contains powerful personal accounts of instances of hostility, marginalisation and neglect. In addition, however, it reported statistical data along the following lines:

Interviewees' Experiences with Abuse and Violence

Abuse / Violence Context	N	%
Abuse and violence experienced in the **family context:**		
By the interviewee her/himself	34	35.8%
By other persons with disability known to the interviewee	12	12.6%
Abuse and violence experienced in **relationships with public authorities:**		
By the interviewee her/himself	11	11.6%
By other persons with disability known to the interviewee	3	3.2%
Abuse and violence experienced **at school:**		
By the interviewee her/himself	7	7.4%
Abuse and violence experienced in the **community and in society at large**		
By the interviewee her/himself		
By other persons with disability known to the interviewee	54	56.8%
	9	9.5%
Situations of abuse and violence experienced in the **workplace**		
By the interviewee her/himself	24	25.3%
By other persons with disability known to the interviewee	8	6.3%

and…

Interviewees' Experiences of Limited Access

Limited access	N	%
Barriers and obstacles in **communicating** with others		
Faced by the interviewee	15	15.8%
Barriers and obstacles in accessing **education**		
Faced by the interviewee	32	33.7%
Faced by others	4	4.2%
Barriers and obstacles in **accessing public services and authorities**		
Faced by the interviewee	6	6.3%

Barriers and obstacles in **accessing the physical environment (including transportation)** Faced by the interviewee Faced by others	30 4	31.6% 4.2%
Barriers and obstacles in **accessing work** Faced by the interviewee	21	22.1%
Poverty	38	40.0%
Obstacles, and negative experiences that are religion-related	6	6.3%

While such statistical information is interesting in its own right, its value as the basis of comparisons over time, between countries or between disabled and non-disabled people is not beyond question. This will depend on the use of robust and consistent methodology in relation to, for instance, selecting the sample of disabled people to be interviewed. In order to facilitate the use of such methodology, DRPI is also working on the production of a range of training guides and materials on various aspects of project design, implementation and analysis. As yet, however, these guides are not available from the DRPI website.

The third and final focus of DRPI monitoring is the monitoring and depiction of disability by the media. This is an issue to which the CRPD will require all Parties to have regard. Article 8 places an obligation on Parties to promote a positive attitude towards disabled people and Article 8(2)(c) provides, by way of an example of a step that this will require:

> (c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention.

The monitoring tool on which DRPI is working will therefore be of great interest. It has not yet been released, however.

In short, DRPI is currently engaged in the process of finalising a number of guides and tools to assist in the process of monitoring disability rights. These instruments are likely to make an important contribution to the international debate and may well provide considerable assistance to the EU in connection with the development of its monitoring strategies and indicators.

4.4 European Blind Union Legislative Database

Monitoring activities have also been conducted by impairment specific organisations. The European Blind Union is currently engaged in compiling a database detailing the extent to which the legislation in EU Member States confers and ensures the rights set out in the CRPD. The first stage of this project (identification of visual-impairment specific requirements emanating from different Articles in the CRPD) has been completed[45]. Similar forms of activity are also to be found, in the context of other impairments, in the work of other European disability organisations (such as Inclusion Europe).

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[45] Available at http://www.euroblind.org/fichiersGB/statements.html

The second phase of EBU's legislative database project is currently underway. It requires information to be gathered, from each of the countries covered, as to the extent to which the CRPD requirements are met by national legislation.

Details of that legislation is also to be included. This information is currently being gathered by national representatives of blind people

The form of monitoring used in the EBU legislative database, like that used in the Special Rapporteur's Global Survey, is structured around the existence of specified legislative measures. It has the potential to provide much useful information as to the extent of CRPD implementation in relation to specific impairment groups and also to provide a useful platform for campaigning. Its usefulness will depend on the quality of the information provided by the national representatives (not all of whom are experts in relevant fields of law). It will also depend on the extent to which the database will accommodate information about the effectiveness and practical impact of legislative measures which have been adopted.

There would be scope to consult and involve such single impairment organisations in elaborating the differentiation of European level indicators.

4.5 The Mental Disability Advocacy Guardianship Project

MDAC conducted a series of investigations into the guardianship regimes of a range of Central and Eastern European countries and produced country reports for each.[46] The issue of guardianship is directly linked to Article 12 of the CRPD but also has implications for many other CRPD rights. It is an issue that tends to impact most dramatically upon the lives of people with intellectual or psychosocial impairments but which often affects people with other forms of impairment as well.

For each country, a local lawyer was appointed to conduct the research. The aim was to examine the degree of compliance of national guardianship regimes with international human rights law. The indicators selected for this study were derived from various instruments of international and European law. They are set out in the following table:

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[46] Available at
http://www.mdac.info.reports .

Summary Table of Indicators

Indicator 1	*Legislative purpose or preamble to the law encompasses respect for the human rights, dignity and fundamental freedom of people with mental disabilities.*
Indicator 2	*The legislation clearly identifies who may make an application for appointment of a guardian and the foundation needed to support it.*
Indicator 3	*An adult has a right to actual notice, and to be present and heard at all proceedings related to the application for deprivation of his or her legal capacity and appointment of a guardian.*
Indicator 4	*An adult has a right to free and effective legal representation throughout guardianship proceedings.*
Indicator 5	*An adult may not be detained in order to be subjected to an evaluation of his or her legal capacity*
Indicator 6	*An adult has the right and opportunity to present his/her own evidence (including witnesses), and to challenge the opposing evidence (witnesses).*
Indicator 7	*No adult is deprived of legal capacity without being the subject of a capacity evaluation, conducted by a qualified professional and based upon recent, objective information, including an in-person evaluation.*
Indicator 8	*A finding of incapacity requires a demonstrable link between the underlying diagnosis and the alleged inability to make independent decisions.*
Indicator 9	*A finding of incapacity is based upon sufficient evidence and serves the interests of the adult.*
Indicator 10	*Selection of a guardian is based on objective criteria and the wishes and feelings of the adult are considered.*
Indicator 11	*The guardian should not have a conflict of interest with the adult, or the appearance of such a conflict.*
Indicator 12	*An adult has the right to appeal a finding of incapacity and/or the appointment of a guardian.*
Indicator 13	*By being placed under guardianship, an adult is not automatically deprived of the opportunity to exercise political rights*
Indicator 14	*By being placed under guardianship, an adult is not automatically deprived of the opportunity to exercise the right to work.*
Indicator 15	*By being placed under guardianship, an adult is not automatically deprived of the opportunity to exercise the right to property.*
Indicator 16	*By being placed under guardianship, an adult is not automatically deprived of the opportunity to exercise the right to marry, to found a family, and to respect of family life.*
Indicator 17	*By being placed under guardianship, an adult is not automatically deprived of the opportunity to exercise the right to associate.*
Indicator 18	*A person under guardianship is not precluded from making decisions in those areas where he/she has functional capacity.*
Indicator 19	*An adult subject to guardianship must be consulted about major decisions, and have his/her wishes adhered to whenever possible.*
Indicator 20	*The scope of authority and obligations of the guardian are clearly defined and limited to those areas in which the adult subject to guardianship needs assistance.*

Indicator 21	*A guardian is obliged to promote the interest, welfare and independence of the adult under guardianship by seeking the least restrictive alternatives in living arrangements, endeavouring to allow the adult to live in the community.*
Indicator 22	*The guardian must manage the assets of the adult in a manner that benefits the adult under guardianship*
Indicator 23	*The guardian is obliged to visit and confer with the adult periodically.*
Indicator 24	*A guardian's decisions are periodically reviewed by an objective body and the guardian is held accountable for all decisions.*
Indicator 25	*A complaint procedure exists that triggers review of guardian's acts or omissions.*
Indicator 26	*Less restrictive alternatives to guardianship are available and are demonstrably exhausted before a guardianship is imposed.*
Indicator 27	*Guardianships are tailored to the individual needs of the person involved and address the varying degrees of capacity.*
Indicator 28	*Guardianship is periodically reviewed and continues only as long as appropriate.*
Indicator 29	*An adult subject to guardianship has the right to request modification and/or termination of the guardianship*

These Guardianship reports are interesting from the perspective of monitoring CRPD implementation, not only because of their content, but also because they demonstrate the use of a more detailed set of indicators relating to the adoption and operation of laws and policies than that revealed in the monitoring projects considered so far. They are evidently limited in scope in that they address only one issue – albeit an issue of fundamental significance in this case.

4.6 The UK Office for Disability Issues' Initial Indicator Set

In the Life Chances Report 2005,[47] the UK Government set out its key aims for ensuring disability equality by 2025. The Office for Disability Issues (ODI) was established to co-ordinate this process. It continues to assert that:

> The government's vision is that by 2025 all disabled people should have the same opportunities and choices as everyone else. Disabled people should be respected as equal members of society and be able to participate as equals in every aspect of family and community life.[48]

The overlap between such a target and the aims of the CRPD is obvious.

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[47] Prime Ministers Strategy Unit, *Improving the Life Chances of Disabled People* (London, Stationery Office, 2005), available at
www.cabinetoffice.gov.uk/strategy

[48] Office for Disability Issues, Annual Report 2007 (London, Stationery Office, 2007) Introduction.

In December 2007, the ODI published a preliminary set of indicators to be used in measuring progress towards the government's stated aim.[49] This followed a period of consultation with disabled people about areas of life which they regarded as particularly important to be included in such a process.[50] A summary of the indicator set reads as follows[51]:

Measures: disabled children and young people

- Use of childcare
- Unauthorised absence from school
- Achievement at Key Stage 2
- Achievement at Key Stage 3
- The percentage of 16 year olds achieving 5 A*-C grade GCSEs
- The proportion of 16 year olds studying for Level 3 qualifications
- The proportion of young people who achieve Level 3 qualifications by age 18
- Proportion of young people with experience of higher education by age 19
- The proportion of first degree qualifiers attaining a first or upper second-class degree
- The proportion of students who do not continue in higher education after their first year
- Satisfaction with higher education courses
- The first destination of graduates 6 months after graduating
- Percentage of children living in income poverty
- Material deprivation

Measures: employment

- Employment rates
- Employment rates of disabled people, by main impairment type
- Economic activity
- Employment by occupation
- The percentage of working age people who have never had a paid job
- The percentage of working age people in work who would like to work more hours at basic pay rate
- Hourly wage rates
- Percentage of working age population with at least Level 2 qualifications or equivalent
- Unfair treatment at work

Measures: independent living

- Full size buses with low floor wheelchair access
- Percentage of disabled people experiencing any difficulties in using transport related to their health problem or disability
- Volunteering
- Civic participation

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[49] Ibid.

[50] The results are set out in E Emerson, S Baines and C Hatton, Disability Equality: How will we Know we are Making a Difference – Summary of the Results of Consultation (London, ODI, 2007).

[51] Office for Disability Issues, Annual Report 2007 (London, Stationery Office, 2007) ch 6.

- Percentage of households with access to the internet
- Participation in cultural, sporting and leisure activities
- Awareness of the DDA in the general population
- Difficulties in accessing goods and services
- Suitability of accommodation for disabled people requiring adaptations to their home
- Percentage of households living in non-decent accommodation
- Individuals living in income poverty
- Fuel poverty
- Psychosocial wellbeing

This list of indicators is explained more fully in Annex 2 of the ODI's 2007 Annual Report where baseline statistics are also provided in relation to each of them.

The ODI developed this list of indicators with a number of considerations in mind. It had regard to the areas of life identified in the Consultation. In addition, it restricted its choice of indicators to ones which satisfied the following criteria[52]:

- information is available to provide a measure
- outcomes for disabled people can be identified separately to outcomes for non-disabled people
- outcomes can be measured over time
- a change in the measure clearly represents progress towards equality.

The ODI’s preliminary set of indicators have considerable merit. They are clearly focused on the measurement of the gap between disabled and non-disabled people in relation to a number of important aspects of life. As such, they promise to provide a valuable mechanism for measuring the extent of the barriers facing disabled people in relation to the areas covered. The fact that performance against each of them is to be assessed annually is also extremely helpful. Because the indicators have been chosen to coincide with information which is already available, it will be possible to begin this process with immediate effect.

The ODI’s indicator set also has obvious limitations as a means of monitoring CRPD rights. It is clearly not comprehensive – being driven by the current availability of relevant information. For instance, it does not specifically cover access to health services and neither does it cover the numbers of people living in residential institutions or being educated in segregated systems or establishments. Neither, with the exception of higher education, does it contain measures of satisfaction or personal experience.

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[52] Ibid.

5. Overview of Types of Indicator Required for Effective CRPD Monitoring

5.1 Statistical Indicators

The most obvious form of indicator (and the most easily measurable and comparable) is statistical. Indeed, this is sometimes considered to be the only form of indicator. Thus, in the words of the Irish National Disability Authority:

> An indicator is a statistical measure that throws light on an issue in a simple and compact way, and tracks change over an extended period of time.[53]

Statistical indicators, based on surveys of a population or environment, may be objective measurements or based on the subjective experience of individuals. It is likely that a combination of both forms will be required to monitor implementation of CRPD rights. Examples of the way in which this might operate in the context of education (Article 24) are outlined here for illustration (some illustrative suggestions are also included later in relation to other areas of the Convention).

5.1.1 Examples of Objective Statistical Indicators

- The percentage of disabled children (broken down into impairment group, gender, ethnicity and region) attending mainstream school.
- The percentage of disabled children (appropriately broken down) attending special school as boarders
- The percentage of disabled children (appropriately broken down) attending special school as day pupils
- The percentage of disabled children (appropriately broken down) and of non-disabled children (appropriately broken down) being formally educated at home
- The percentage of disabled children (appropriately broken down) and of non-disabled children (appropriately broken down) not being formally educated
- --The percentage of disabled children (appropriately broken down) within each of the above categories attaining the average grades for non-disabled children at various key stages
- The percentage of students in various post-16 forms of education who are disabled (appropriately broken down)
- The percentage of educational establishments which meet agreed criteria for physical accessibility
- The percentage of school books available in alternative formats
- The percentage of teachers who will have received training in disability-awareness issues.

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[53] *National Disability Authority*, How Far Towards Equality? Measuring how Equally People with Disabilities are Included in Irish Society (Dublin, NDA, 2005)h 9.

5.1.2 Examples of Experience-Based Statistical Indicators

- The percentage of disabled people of a particular age (appropriately broken down into impairment group, gender, ethnicity etc) and of non-disabled people of that age who are happy at school/college
- The percentage of those people who have been bullied at school/college
- The percentage of those disabled and of those non-disabled people who have been bullied and felt that the situation was helpfully managed by the school/college
- The percentage of disabled people of a particular age (appropriately broken down into impairment group, gender, ethnicity etc) who believe that the grades they are able to obtain in formal assessments is less than it would have been had all the impairment-related barriers been removed through effective and appropriate adjustments or support
- The percentage of disabled school leavers who express the view that, had it not been for impairment-related concerns, they would have continued their studies.

5.2 Law and Policy Indicators

5.2.1 Overview

In addition to comparative statistical information, effective monitoring of the CRPD is likely to require reference to indicators based on the existence of particular legal or policy measures. It is indicators of this type that were used in the Special Rapporteur's Global Survey on the Implementation of the Standard Rules. They also feature in the methodologies of the DRPI (where they are referred to as the 'systems' focus) and the IDRM.

Some assistance in the identification of relevant indicators of this type may be derived from the Global Survey on the Standard Rules. However, the CRPD is, in many respects, more far-reaching than the Standard Rules and will therefore require States to demonstrate that they have taken additional legal, policy or administrative measures. The recent report produced by the International Disability Alliance CRPD Forum for the OCHCR[54] sets out a long and detailed list of laws and policies that implementation of the CRPD will require. Accordingly, it provides a convenient source of potential indicators of this sort.

5.2.2 Examples of Law and Policy Indicators

Examples of indicators of this sort might include the following:

- Does your country have a law prohibiting discrimination against disabled people?
- Does your country have a law requiring employers/education-providers/providers of other goods and services to provide reasonable accommodation measures for disabled people?
- Does your country have a system of plenary guardianship?
- Does your country have a system of supported decision-making?
- Does your country have a policy of allowing disabled people to send information to (and receive it from) public bodies in formats of their choice?

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[54] http://www.internationaldisabilityalliance.org/forum.html

5.2.3 Independent Expert Input

The indicators described so far provide useful but limited information. As is well known, the mere existence of a law or a policy reveals little about its dimensions, its interpretation and its effect in practice.

Important additional information might therefore be gleaned from experts in the field. Suitably qualified lawyers, for instance, might be able to explain the scope and effect of relevant legal provisions (together with any accompanying regulations or case-law). This is the basis on which the MDAC Guardianship Project was conducted and on which the EU Network of Experts on Non-Discrimination Law operates. The reports emerging from both these sources clearly illustrate the potential value of such expert input and evaluation. Similarly, engagement of country experts from the Academic Network of European Disability experts (ANED) is likely to prove extremely valuable in reporting on policy implementation and research evidence. Rapporteurs from disabled people's organisations must also be considered as a potential key resource.

Securing expert input would undoubtedly enhance the monitoring and implementation process. It would, however, produce information that could not be easily translated into simple indicators. Nevertheless, consideration should be given to the production of qualitative reports as an essential supplement to the use of statistical data and criterion based law and policy indicators.

5.2.4 Personal Experience Input

Invaluable information about the impact of law and policy is to be derived from the views of people with direct experience of their operation. The manner in which such views may be obtained will vary according to the context and the circumstances. It may, on occasion, be possible to use survey techniques based on the types of question outlined in Section 5.1 above. This, however, will not always be the case – perhaps because of difficulty associated with identifying the relevant group or because of difficulty associated with the willingness or ability of people in such groups to participate actively in the survey.

The importance of including personal experience in the monitoring process is stressed by DRPI. It draws attention to the need to allow people to describe their experience without being constrained to describe only one particular aspect of it – e.g. that relating only to employment or to education. The issue of accessing rights is a complex and multifaceted one which does not necessarily break down into neatly categorised fields. Accordingly, it relies heavily on information obtained from accounts and interviews (e.g. conducted by disabled people with disabled people)[55].

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[55] See further DRPI, *Moving Forward: Progress in Global Disability Rights Monitoring* (York University Toronto,DRPI, 2007)ch 3.

It may, in some contexts, be helpful to gain experience-based information about the impact of laws or policies by techniques such as ‘mystery shopping’. In some contexts (such as public transport, residential institutions or access to public information) teams of inspectors (including disabled people) with relevant experience and expertise would be well placed to gather information on the extent to which human rights are actually being enjoyed in practice[56].

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[56] See further Mental Disability Advocacy Centre, *Inspect: Inspectorates of Mental Health and Social Care Institutions in the European Union* (Budapest, MDAC, 2006), available at http://www.mdac.info.reports .

6. Conclusion

This report establishes a preliminary orientation to the key demands and challenges arising from the monitoring requirements of the UNCRPD. It also provides first indications of the requirements for developing monitoring indicators. More detailed work and investment in resources is now required to take this work forward, to develop a preliminary list of indicators, to consult on these, and to match them with available sources of data.

In summary, the key conclusions are as follows:

- Monitoring bodies will require guidance on appropriate indicators, and access to robust data. Such approaches should be consistent with the requirements of the UN Committee and state reporting mechanisms. Joined-up monitoring practice will not be easily achieved and it will be important to establish dialogue between the European Commission, relevant state parties and the research community.
- Appropriate indicators of outcome should allow for comparisons over time, between disabled and non-disabled people (between different groups of disabled people), and between countries.
- Longitudinal measurement of progress requires baseline measurements of the current situation. Immediate work is required to begin developing indicators and identifying relevant data sources for this purpose (including the specification of new data collection demands where necessary).
- European institutions can play a key role in defining, collating and reporting comparative data between countries.
- Indicators should be drawn from both generic population data (including appropriate disability variables) and targeted surveys of disabled people.
- There is a need to identify people with ‘long-term’ impairments, and to measure the impact of ‘barriers’ on their ‘participation’ in key areas, and to compare this with ‘others’ in the population. Each dimension should be evident in the selected indicators.
- Where relevant, the identification of disabled people in measures and indicators needs to capture significant dimensions of difference and intersectionality (e.g. impairment, age, gender, ethnicity, religion, and sexual orientation).
- Indicators should include measurements of participation restriction and disabling barriers that inhibit the full enjoyment of particular rights. New approaches to measurement and indicators relating to disabling barriers will need to be developed as a matter of urgency.
- Monitoring should include qualitative indicators concerning the existence of specific legal and policy provisions in relevant areas.
- Statistical indicators based on both objective measurements and subjective experiences will be relevant to the task.
- Simple indicators should be supplemented with independent qualitative reports on key areas of implementation, engaging suitable field experts and disabled people’s organisations.
- Using the Convention as a framework of key areas, a provisional list of monitoring indicators should be identified by an expert group which includes representatives of disabled peoples organisations.

- A short list of key indicators should be selected, with the involvement of disabled people’s organisations, as the basis for publishing a standardised ‘scorecard’ for each country.

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Annex 2: Extract: Preliminary Indicators for Monitoring the Convention on the Rights of Persons with Disabilities

(Extract from P French, Human Rights Indicators for People with Disability: A *Resource for Disability Activists and Policy Makers (Queensland, Queensland Advocacy Inc, 2008))*

Article	**Human Right Indicators**
Convention on the Rights of Persons with Disabilities	
Article 1: Purpose	• The human rights and fundamental freedoms set out in the CRPD apply to all persons with disability. • All human rights and fundamental freedoms are promoted, protected and fulfilled. • The inherent dignity of persons with disability is promoted and respected
Article 3: General principles	• All human rights and fundamental freedoms of persons with disability are interpreted and implemented in a manner consistent with the following general principles: • Respect for the inherent dignity, individual autonomy, including freedom to make one's own choices, and independence of persons; • Non-discrimination; • Full and effective participation and inclusion in society; • Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; • Equality of opportunity; • Accessibility; • Equality between men and women; • Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.
Article 4: General obligations	• All human rights and fundamental freedoms of persons with disability are promoted, protected and fulfilled by laws, policies and programmes. • All laws, regulations, customs and practices that constitute discrimination on the ground of disability have been modified or abolished. • All policies and programmes take into account the promotion and protection of the human rights and fundamental freedoms of persons with disability. • All action and practices of public authorities and institutions is consistent with the human rights and fundamental freedoms of persons with disability.

	• There is no discrimination on the ground of disability by any person, organisation or private enterprise. • Research and development of universally designed goods, services, equipment and facilities is undertaken or promoted. • The availability and use of universally designed goods, services, equipment and facilities is promoted. • The use of universal design in the development of standards and guidelines is promoted. • Research and development of new technologies, mobility aids, devices, and assistive technologies for persons with disability is undertaken and promoted. • The availability and use of new technologies, mobility aids, devices, and assistive technologies for persons with disability is promoted. • Priority is given to research and development of technologies with an affordable cost to persons with disability. • Accessible information is provided to persons with disability about mobility aids, devices and assistive technologies, other forms of assistance, support services and facilities. • Professionals and staff working with persons with disability are trained to recognise and facilitate the realisation of the human rights and fundamental freedoms of persons with disability. • The full realisation of economic, social and cultural rights is pursued to the maximum extent of available resources. • The full realisation of economic, social and cultural rights is pursued within a framework of international cooperation, where necessary. • The civil and political rights of persons with disability are immediately realised. • Representative organisations for children and adults with disability are closely consulted and actively involved in the development and implementation of legislation and policies to implement the CRPD and all other decision-making processes concerning issues relating to persons with disability. • Existing provisions, which are more favourable than those provided the CRPD, are preserved. • The human rights and fundamental freedoms of persons with disability are recognised in all parts of Australia's federal system without any limitations or exceptions.
Article 5: Equality and non-discrimination	• The law is the same for persons with disability as it is for others. • The law is applied to persons with disability in the same way as it is applied to others. • The law shields persons with disability from harm in the same way it does for others. • Persons with disability are able to use the law to protect or pursue their interests on an equal basis with others. • Discrimination on the ground of disability is prohibited.

	• Persons with disability are effectively protected from discrimination on the ground of disability, and on all other grounds. • All appropriate steps are taken to ensure the provision of reasonable accommodation of the needs of persons with disability. • Positive measures designed to promote and achieve equality for persons with disability are excepted from the prohibition of discrimination on the ground of disability.
Article 6: Women with disabilities	• The pre-existing gender inequality of women and girls with disability is recognised in all aspects of CRPD implementation effort. • Women and girls with disability enjoy all human rights and fundamental freedoms on the basis of equality with men and boys. • Positive measures are in place to ensure the development, advancement and empowerment of women and girls with disability, and their ability to exercise their human rights and fundamental freedoms.
Article 7: Children with disabilities	• Children and young persons with disability enjoy all human rights and fundamental freedoms on an equal basis with other children. • In all action concerning children and young persons with disability, the best interests of the child is a primary consideration. • The evolving autonomy of children and young persons with disability is recognised in all decision-making processes that affect them. • Children and young persons with disability are able to express their views on all matters that affect them. • The views of children and young persons with disability are given appropriate weight in all decision-making processes. • Reasonable accommodation is provided to children and young persons with disability where required to ensure their ability to participate in decision-making processes on an equal basis with other children. • Age-related accommodations are provided to children and young persons with disability on an equal basis with other children to ensure their ability to participate in decision-making processes.
Article 8: Awareness-raising	• The human rights and dignity of persons with disability are recognised and respected at all levels of society and in all areas of life. • The community is receptive to the human rights of persons with disability. • The community has positive perceptions of persons with disability.

	• Stereotypes, prejudices and harmful practices relating to persons with disability are effectively combated at all levels of society and in all areas of life. • The capability and contribution of persons with disability is effectively promoted at all levels of society and in all areas of life. • The media portrays persons with disability in a manner that is consistent with their human rights and dignity.
Article 9: Accessibility	• Persons with disability are able to access all aspects of the environment on an equal basis with others, including: • Public and private buildings and facilities, including schools, housing, medical facilities and workplaces; • Information and communications, including information and communication technologies and systems; • Transport and transport infrastructure. • Barriers and obstacles to accessibility of public facilities and services are identified in eliminated. • Standards and guidelines are in place and are enforced to ensure the accessibility of public services and facilities. • Standards and guidelines for accessibility apply to both government and private entities providing public services and facilities. • Training on accessibility issues for persons with disability is provided to all relevant stakeholders (for example, architects, planners, and engineers). • Signage in public buildings is available in Braille, and in easy to read and comprehend formats. • Live assistance and intermediaries (such as guides, readers and sign language interpreters) are available to facilitate accessibility to public buildings and facilities. • Any other necessary assistance is available to persons with disability to ensure their access to information. • Persons with disability have access to new information and communications technologies and systems, including the Internet. • Information and communication technologies and systems are from the outset designed, developed, produced, and distributed so as to incorporate accessibility features. • Information and communication technologies and systems may be made accessible to persons with disability at minimum cost.
Article 10: Right to life	• Persons with disability enjoy the right to life and survival on an equal basis with others. • All necessary measures are taken to ensure that persons with disability enjoy the right to life and survival on an equal basis with others. • Persons with disability are not arbitrary deprived of life, including as a result of discrimination on the ground of disability. • The right to life is protected by law (and these laws are effective in relation to persons with disability).

Article 11: Situations of risk and humanitarian emergencies	• All necessary measures are taken to ensure the protection and safety of persons with disability in situations of risk.
Article 12: Equal recognition before the law	• All persons with disability are recognised at all times and in all situations as persons with legal rights and duties. • Persons with disability are able to exercise legal capacity on an equal basis with others. • Persons with disability receive any support they may require to exercise their legal capacity. Any such support: • Respects the rights, will and preferences of the person; • Is free from conflict of interest and undue influence; • Is proportionate to the person's need for such support (that is, is the least restrictive necessary); • Is individualised; • Is provided only for the period necessary; and • Is subject to regular review by an independent and impartial authority. • Persons with disability are able to own and inherit property. • Persons with disability have access to credit on an equal basis with others. • Persons with disability are not deprived of their property without proper lawful reason. • Persons with disability are able to control their own financial affairs on an equal basis with others. • Persons with disability receive any support they may require to manage their financial affairs. Any such support: • Respects the rights, will and preferences of the person; • Is free from conflict of interest and undue influence; • Is proportionate to the person's need for such support (that is, it is the least restrictive necessary); • Is individualised; • Is provided only for the period necessary; and • Is subject to regular review by an independent and impartial authority.
Article 13: Access to justice	• Persons with disability enjoy effective access to justice at all stages of the legal process. • Procedural accommodations are made in the legal process to ensure effective participation of persons with disability in the justice system in whatever role in which they encounter it. • Age-related accommodations are made to the legal process to ensure effective participation of children and young persons with disability. • Appropriate training is provided to all justice agency personnel to ensure access to justice for persons with disability.

Article 14: Liberty and security of the person	• Persons with disability enjoy personal freedom on an equal basis with others. • Persons with disability are free from interference with their person on an equal basis with others. • Persons with disability are not deprived of liberty without lawful and proper reason. • The existence of impairment or disability (of itself) is never a reason for deprivation of liberty. • Persons with disability deprived of their liberty enjoy fully their remaining human rights. • Reasonable accommodation is provided to persons with disability deprived of their liberty to ensure their full enjoyment of their remaining human rights.
Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment	• Persons with disability are effectively protected from torture, and from cruel, inhuman, and degrading treatment. • Persons with disability are not subject to medical or scientific experimentation without their consent. • Persons with disability who do not have the capacity to consent are subject to special protection from medical and scientific experimentation. • All effective measures are taken to protect persons with disability from torture, and from cruel, inhuman and degrading treatment
Article 16: Freedom from exploitation, violence and abuse	• Persons with disability are effectively protected from all forms of exploitation, violence and abuse. • Protection from exploitation, violence and abuse is effective both within and outside the home (that is, both in the public and private spheres). • Women and girls with disability are effectively protected from all forms of exploitation, violence and abuse that have a gender dimension. • Children and young persons with disability and older persons with disability are effectively protected from all forms of exploitation, violence and abuse that have an age dimension. • Persons with disability, their families and carers are effectively informed and educated in relation to strategies to avoid, detect and report all forms of exploitation, violence and abuse. • There are effective laws and policies that ensure that harms against persons with disability are identified, investigated and prosecuted. • Laws, policies, programmes, protective and other services that relate to the prevention, detection, investigation and prosecution of harms against children and adults with disability are age, gender and disability sensitive. • All specialist facilities and programmes for persons with disability are effectively monitored by independent authorities to safeguard against exploitation, violence and abuse of persons with disability.

	• Persons with disability who are victims of harm have access to effective recovery, rehabilitation and social re-integration programmes and services. • Recovery, rehabilitation and reintegration programmes for persons with disability who are victims of harm are provided in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person. • Recovery, rehabilitation and reintegration programmes for persons with disability who are victims of crime are responsive to age and gender-related needs.
Article 17: Protecting the integrity of the person	• Persons with disability are not subject to interference with their physical integrity. • Persons with disability not subject to interference with their mental integrity.
Article 18: Liberty of movement and nationality	• Persons with disability enjoy liberty of movement within and across national borders on an equal basis with others. • Persons with disability are able to choose their own residence on an equal basis with others. • Persons with disability are able to choose their nationality on an equal basis with others. • Children with disability are registered immediately after birth. • Children with disability are named from birth. • Children with disability acquire a nationality from birth. • Children with disability know and are cared for by their parents from birth.
Article 19: Living independently and being included in the community	• Persons with disability live in the community with choices equal to others. • Persons with disability are included, and participate, in the community. • Persons with disability are able to choose their place of residence on an equal basis with others. • Persons with disability are able not obliged to live in any particular living arrangement. • Persons with disability have access to a range of in-home, residential and other community support services necessary to support living and inclusion in the community and to prevent isolation and segregation from the community. • Community services and facilities for the general population are available to persons with disability on an equal basis with others and are responsive to their needs.
Article 20: Personal mobility	• Persons with disability enjoy personal mobility with the greatest possible independence. • Persons with disability are able to mobilise in the manner and at the time of their choice. • Persons with disability are able to mobilise at an affordable cost. • Persons with disability have access to quality mobility aids, devices and assistive technologies.

	• Persons with disabilities have access to live assistance and intermediaries. • Persons with disability are effectively trained in mobility skills. • Staff who work with persons with disability are effectively trained in mobility skills. • There are mobility aids, devices and assistive technologies to support all aspects of mobility for persons with disability.
Article 21: Freedom of expression and opinion, and access to information	• Persons with disability enjoy freedom of expression on an equal basis with others. • Persons with disability enjoy freedom of opinion on an equal basis with others. • Persons with disability have freedom to seek, receive and impart information and ideas on an equal basis with others. • Persons with disability are able to seek, receive and impart information and ideas through all forms of communication of their choice. • Public information is available to persons with disability in accessible formats. • Public information is accessible to persons who use assistive communication devices. • Public information is made available in accessible formats in a timely manner and without additional cost. • Alternative modes, means and formats of communication are accepted and facilitated in official interactions with persons with disability. • Public information and services provided by the private sector are accessible to persons with disability. • The mass media is accessible to persons with disability. • The Internet is accessible to persons with disability. • Australian Sign Language is officially recognised and its use is promoted.
Article 22: Respect for privacy	• Persons with disability are free from arbitrary or unlawful interference with their privacy, irrespective of their living arrangements. • Persons with disability are free from arbitrary or unlawful interference with their family life. • Persons with disability are free from arbitrary or unlawful interference with their home. • Persons with disability are free from arbitrary or unlawful interference with their correspondence and other forms of communication. • Persons with disability are free from unlawful attacks on their honour and reputation. • The law effectively protects persons with disability from interference with all aspects of their privacy. • The law effectively protects persons with disability from attacks on their honour and reputation.

	• The law effectively protects the privacy of personal, health and rehabilitation information of persons with disability on an equal basis with others.
Article 23: Respect for home and the family	• Persons with disability do not experience discrimination in relation to any matter concerning marriage, family, parenthood and relationships. • Consenting adults with disability are able to marry and found a family. • Persons with disability are able to decide on the number and spacing of their children. • Persons with disability have effective access to family planning information and education, including in accessible and adapted formats if required. • Persons with disability, including children with disability, retain their fertility on an equal basis with others. • Persons with disability are accorded the same rights and responsibilities as others with respect to the guardianship and adoption of children. • The 'best interests of the child' is the paramount consideration in all decisions concerning guardianship and adoption. • Persons with disability have access to appropriate assistance, where necessary, to assist them with the performance of their child-rearing responsibilities. • Children with disability are accorded the same rights as other children to family life. • Children with disability are effectively protected from concealment, abandonment, neglect and segregation. • Children with disability and their families are effectively supported with early intervention, comprehensive information, and services and support. • Children with disability are not arbitrarily or unlawfully separated from their parents against their will. The 'best interests of the child' is the basis for any such separation. • Children with disability are not separated from their parents on the basis of the disability of either the child or of one or both parents. • Children with disability unable to live with their immediate family are provided with alternative care within their wider family, or if this is not possible, within the community in a family setting.
Article 24: Education	• Persons with disability are accorded the right to education. • Persons with disability are free from discrimination on the ground of disability in education. • Education of persons with disability is inclusive at all levels of the education system. • Persons with disability have access to life long learning, including general tertiary education, vocational training and adult education.

	• Education is directed to: • The full development of human potential and sense of dignity and self worth; • Strengthening of respect for human rights, fundamental freedoms, and human diversity; • The development of personality, talents and creativity, and mental and physical abilities, to their fullest potential; • Enabling persons with disability to participate effectively in a free society. • Persons with disability are not excluded from the general education system on the basis of disability. • Persons with disability are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability. • Persons with disability 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. • Students with disability are provided with reasonable accommodation of their impairment and disability related needs. • Students with disability receive the support they require to facilitate their effective education within the general education system. • Students with disability receive effective individualised support measures in fully inclusive environments that maximise academic and social development. • Persons with disability have access to life and social development skills education to facilitate their full and equal participation in education and as members of the community. • Persons with disability have the opportunity to learn: • Braille, alternative script, augmentative and alternative modes, means and formats of communication; • Orientation and mobility skills; and • Sign languages. • Persons with disability have access to peer support and mentoring. • The linguistic identity of the Deaf community is promoted in educational settings. • Education for children who are blind, deaf or deafblind is delivered in appropriate languages, including sign languages, and other modes and means of communication appropriate for the individual. • Teachers are qualified in Australian sign language and proficient in the use of Braille. • Staff at all levels of the education system are educated in disability awareness and in the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support students with disability.

Article 25: Health	• Persons with disability enjoy the highest attainable standard of health. • Persons with disability do not experience discrimination in any aspect of the health system. • Health services, including health-related rehabilitation services, are gender sensitive. • Persons with disability have access to the same range, quality and standard of free or affordable health care and programmes as other persons. • Persons with disability have access to the same range, quality and standard of free or affordable sexual and reproductive health care and programmes as other persons • Persons with disability have access to the same range, quality and standard of population-based public health programmes as other persons. • Persons with disability have access to any specialist health services they require, including early identification and intervention services, and services designed to minimise or prevent further disability. • Health services are available in local communities, including in rural areas. • Health professionals provide the same quality of care to persons with disability as to others. • Health professionals are educated to raise awareness of the human rights, dignity, autonomy and needs of persons with disability. • Health care is provided only on the basis of the free and informed consent of the person with disability receiving treatment. • There are health care ethical standards in place for public and private health care that ensure that persons with disability receive the highest attainable health care without discrimination. • Discrimination on the ground of disability in the provision of health insurance and life insurance is prohibited. Such insurance is available to persons with disability on a fair and reasonable basis. • Discriminatory denial of health care or health services, or foods or fluids on the basis of disability, is prohibited.
Article 26: Habilitation and rehabilitation	• Persons with disability have access to habilitation and rehabilitation services that will allow them to: • Attain and maintain maximum independence; • Full physical, mental, social and vocational ability; and • Full inclusion and participation in all aspects of life. • Habilitation and rehabilitation services begin at the earliest possible stage. • Habilitation and rehabilitation services are based on the multidisciplinary assessment of the person's individual needs and strengths.

	• Habilitation and rehabilitation services support persons with disability to participate and be included in the community, and in all aspects of society. • Habilitation and rehabilitation services are available to persons with disability in local communities, including in rural areas. • The participation of persons with disability in habilitation and rehabilitation services is voluntary. • Habilitation and rehabilitation professionals and staff receive comprehensive initial and continuing education. • Persons with disability are informed about, and have ready access to, assistive devices and technologies to assist them with habilitation and rehabilitation.
Article 27: **Work and employment**	• Persons with disability have access to work on an equal basis with others. • Persons with disability have the opportunity to gain a living in a freely chosen or accepted labour market and work environment. • Persons with disability have access to open, inclusive and accessible employment. • Discrimination on the ground of disability is prohibited in all forms and aspects of employment, including: • Conditions of recruitment; • Hiring and employment; • Continuity of employment; • Career advancement; and, • Safe and healthy working conditions. • Persons with disability have access to just and favourable conditions of work on an equal basis with others. This includes • Equal opportunities of work; • Equal remuneration for work of equal value; • Safe and healthy working conditions, including protection from harassment; and • The redress of grievances. • Persons with disability exercise their labour and trade union rights on an equal basis with others. • Persons with disability have effective access to general technical and vocational guidance programs, placement services and vocational and continuing training. • Career opportunities and career advancement for persons with disability are promoted. • Persons with disability are provided with assistance to find, obtain, maintain and return to employment. • Opportunities for self-employment, entrepreneurship, development of cooperatives and personal enterprises are promoted to persons with disability. • Persons with disability are employed in the public sector.

	• There are policies and measures (such as affirmative action and incentives), which promote employment of persons with disability in the private sector. • Persons with disability have access to reasonable accommodation of their impairment and disability related needs in the workplace. • Persons with disability have access to work experience in the open labour market. • Vocational and professional rehabilitation, job-retention and return-to-work programs for persons with disability are promoted. • Persons with disability are not held in slavery or in servitude and are protected from forced or compulsory labour on an equal basis with others.
Article 28: Adequate standard of living and social protection	• Persons with disability have access to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, without discrimination on the ground of disability. • Persons with disability enjoy continuous improvement of living conditions without discrimination on the ground of disability. • Persons with disability have access to social protection without discrimination on the ground of disability. • Persons with disability have access to clean water. • Persons with disability have access to appropriate and affordable services, devices and other assistance for disability-related needs. • Persons with disability have access to social protection and poverty reduction programmes. In particular, women and girls with disability, and older persons with disability, have access to social protection and poverty reduction programmes. • Persons with disability and their families living in situations of poverty have access to assistance with disability-related expenses. • Persons with disability have access to public housing programmes. • Persons with disability have access to retirement benefits and programmes.
Article 29: Participation in political and public life	• Persons with disability effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives. • Voting procedures, facilities and materials are accessible to persons with disability. • Persons with disability are able to vote by secret ballot in elections and public referendums. • Persons with disability are able to vote in elections and public referendums without intimidation. • Persons with disability are able to stand for election, to effectively hold office, and perform all public functions at all levels of government.

	• Persons with disability have access to a personal assistant of their choice to assist in voting. • Persons with disability can effectively and fully participate in the conduct of public affairs on an equal basis with others without discrimination. • Participation of persons with disability in public affairs is encouraged. • Persons with disability are encouraged to participate in non-governmental organisations and associations concerned with public and political life, and in the activities and administration of political parties. • Persons with disability are encouraged to form and join organisations of persons with disability to represent them at the international, national, regional and local levels.
Article 30: Participation in cultural life, recreation, leisure and sport	• Persons with disability take part in cultural life on an equal basis with others. • Cultural materials are available in accessible formats. • Persons with disability have access to television programmes, films, theatre and other cultural activities in accessible formats. • Persons with disability have access to places of cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services. • Persons with disability have access, as far as possible, to monuments and sites of national cultural importance. • Persons with disability have the opportunity to develop and utilise their creative, artistic and intellectual potential. • Intellectual property rights do not constitute an unreasonable or discriminatory barrier to access to cultural materials for persons with disability. • The specific cultural and linguistic identity of persons with disability, including sign languages and deaf culture, is recognised. • Persons with disability participate in recreational, leisure and sporting activities on an equal basis with others. • The participation to the fullest extent possible of persons with disability in mainstream sporting activities at all levels is encouraged and promoted. • Persons with disability have the opportunity and capacity to organise, develop and participate in disability-specific sporting and recreational activities. • Persons with disability have access to sporting, recreational and tourism venues. • Children with disability have equal access with other children to participation in play, recreation and leisure and sporting activities. • Persons with disability have access to services from those involved in the organisation of recreation, tourism, leisure and sporting activities.

Article 31: Statistics and data collection	• Statistical and research data is collected to assist in the formulation and implementation of policies to give effect to the CRPD. • Information collection processes comply with human rights and ethical safeguards, including in relation to the confidentially of personal information. • Information is disaggregated so as to enable it to be used to assess the effectiveness of CRPD implementation efforts in a particular area or with respect to a particular group. • Statistical and research data is disseminated to persons with disability in accessible formats, and to interested others.
Article 32: International cooperation	• The importance of international cooperation for the realisation of the purpose and objectives of the CRPD is recognised and promoted. • International cooperation is undertaken in partnership with civil society, in particular with organisations of persons with disability. • International development programmes are inclusive of and accessible to persons with disability. • Capacity to implement the CRPD is built by engaging in the sharing and exchange of information and experience, training and best practice with other nations. • Capacity to implement the CRPD is built by facilitating cooperation in research and access to scientific and technical knowledge with other nations. • Capacity to implement the CRPD is built by providing economic and technical assistance to other nations. Such assistance includes the provision of access to, and the sharing of, accessible and assistive technologies.
Article 33: National implementation and monitoring	• There are designated focal points and coordination mechanisms within government to facilitate cross-sectoral CRPD implementation. • An independent monitoring mechanism to oversight implementation of the CRPD, which complies with the Paris Principles has been designated or established. • Persons with disability are fully involved, and participate, in national monitoring of implementation of the CRPD.
Article 35: Reports by States Parties	• A comprehensive report to the Committee in relation to Australia's implementation of the CRPD within two years of the CRPD coming into force. • Periodic reports are submitted to the Committee in relation to Australia's implementation of the CRPD every four years or when the Committee requests it to do so. • Reports to the Committee are prepared in an open and transparent manner. • Persons with disability are actively consulted in the preparation of Australia's reports to the Committee.

Article 37: Cooperation between States Parties and the Committee	• Australia cooperates with the Committee on the Rights of Persons with Disabilities.
Article 40: Conference of States Parties	• Australia actively participates in the Conference of State Parties.
Article 43: Consent to be bound	• Australia is a party to the Convention on the Rights of Persons with Disabilities.
Article 46: Reservations	• Australia has not lodged reservations against any aspect of the CRPD.
Optional Protocol to the Convention on the Rights of Persons with Disabilities	
Article 3	• Australia responds to communications received by the Committee on the Rights of Persons with Disabilities within six months of notification of the communication.
Article 4	• Australia takes any interim measures requested by the Committee on the Rights of Persons with Disabilities to avoid irreparable damage to the victim or victims of an alleged violation.
Article 7	• Australia cooperates with the Committee on the Rights of Persons with Disabilities in any inquiry into allegations of grave or systemic violations of the CRPD. • Australia responds to any findings, comments and recommendations arising from an inquiry into allegations of grave or systemic violations of the CRPD within six months of receiving the Committee's report.
Article 11	• Australia is a party to the Optional Protocol to the Convention on the Rights of Persons with Disabilities.
Article 14	• Australia has not lodged reservations against any aspect of the Optional Protocol.

Annex 3: State of Disabled Peoples' Rights in Kenya, 2007 Interview Questionnaire

STEP 1 – Introductions, Background Information, Consent & Collection of Personal Data

1. introduction of monitors

2. review of Project Information Sheet and Free and Informed Consent Form

3. collection of personal information (proceed with questioning ONLY if consent is given)

Collection of Personal Information

- Interview Code:
- Sex:
- Age Range [check one]:
- 18-25
- 26-40
- 41-55
- 56-70
- 71 and older

- Type of Disability [mark as many as apply]:
- mobility
- sensory
- blind
- deaf
- intellectual
- psychiatric
- other (specify)

STEP 2 – Asking the Prompting Questions

1. What are the most difficult barriers or challenges that you face in your life?

2. Have you been left out or treated badly because of your disability?

3. Have you been prevented from participating in activities that you wanted to do?

Which prompting question(s) did you use?

Which prompting question(s) was/were most effective?

DEALING WITH ISSUE / SITUATION #1 RAISED BY THE INTERVIEWEE

STEP 3 - Getting Details About the Issue(s) / Situation(s) Raised

WHAT?

- What happened?
- How did it happen?

WHEN?

- When did it happen? (date, time of day)
- Is it still happening or has it stopped?
- Is this an ongoing situation?

WHERE?

- Where did it happen? (if the situation is specific to a location, get city/village, province/state)
- Did it happen in only one place? In more than one place? (record all of the places)

WHO?

- What type of person caused the situation? (for example: government official, doctor, bus driver, neighbour)

WHY?

- Why did it happen?

REPORTING?

- Did you report the situation to anyone? yes or no
- If you did report the situation:
- What kind of person/organization did you report it to?
- government official
- police officer
- army officer
- N.G.O. employee
- religious leader
- cultural leader
- ombudsperson
- other (specify)
- How did that person react?
- What action was taken?
- If you did not report the situation:
- Why did you not report it?

STEP 4 – Relating the Issue(s) / Situation(s) Raised to the General Human Rights Principles

Dignity

1. Did you feel:

- disrespected? or
- respected? or
- did respect not have anything to do with the way you felt? What made you feel that way?

2. Did you feel that your feelings were ignored or that no one cared for you?

3. Did you feel that people were paying attention to you and your needs? Why or why not?

4. Did this situation make you feel less worthy? Yes or no?

- If yes, what made you feel that way?

5. Did you feel isolated in this situation? Yes or no?

- If yes, what made you feel that way?

Autonomy

1. Did you feel that you had a choice (or that you made a decision on your own)?

- yes
- no

2. Did you have real options in this situation?

- If not, what stopped you from having options?

3. Did you want to make a different decision or did you want to do something else?

4. Did you have enough information to make that decision?

5. Did you feel pressured to act the way you did?

Non-Discrimination & Equality

1. In what way do you think your disability had something to do with what happened?

2. Do you think that people without disabilities would be treated the same way you were? Why?

3. Do you know anyone else who was treated in the way you were? Why?

4. Do you feel that you were treated like you were less valuable than other people in the same situation?

Inclusion

1. Did your community support you in this situation? If so, how?

2. Were you separated from people without disabilities? If so, how?

3. Did you need a service or some assistance so that you could participate?

- If yes, what service(s) or assistance?]
- Did you receive them?

Respect for Difference

1. Were you treated the way you were in this situation because people thought you were different? If yes, why?

2. Do you think that other people would have been treated in a similar way in this situation?

3. Would:

- someone of a different ethnicity be treated that way?
- a woman be treated that way?
- a poor person be treated that way?

4. Do you feel that people label you and then treat you differently because of the label?

FOLLOW-UP INFORMATION

- Is there someone we could contact who saw this happen or who could provide us with more information? Yes or no?
- If yes:
- What is their name? (record name on Coding Sheet)
- Can we contact this person? Yes or no?
- If yes, what is the best way for us to contact him or her? (record details on Coding Sheet)

POSSIBLE SOLUTIONS, WAYS TO AVOID FUTURE VIOLATIONS

In your opinion, what action(s) should be taken to improve or prevent the situation?

SUMMING UP ISSUE#1

Is there anything else that you would like to say about that issue/situation?

NOW, we are going to return to the issue you raised earlier about (insert brief reference to SITUATION / ISSUE #2)

The same set of questions were then re-asked about situation #2 and situation #3 (depending on whether there was sufficient time within the 2 hour time limit specified for the interview.

STEP 5 – Interview Conclusion

1. Do you have anything else you would like to add?

2. Do you have any questions for us?

Thank you very much for your time.

Annex 4: Contact Details for Organisations consulted

The following organisations were approached, or volunteered information, during the task

Disability Rights Promotion International, York University, 5021 T.E.L. Building 4700 Keele Street, Toronto, Ontario M3J 1P3 Canada Telephone: 1-416-736-2100 ext. 20718 Fax: 1-416-736-5986 E-Mail: drpi@yorku.ca	Bengt Lindqvist and Marcia Rioux, Co-Directors Rita Samson, Project Coordinator
International Disability Rights Monitor	Mary Keogh (European director) mkeogh@cirnetwork.org
Global Partnership on Disability and Development (GPDD)	María Verónica Reina, M.A. Executive Director Phone: 202-296-2042 mvreina@law.syr.edu Nakia Matthews, Program Administrator Phone: 202-296-2040
Inclusion Europe Galeries de la Toison d'Or 29 Chaussée d'Ixelles #393/32 B-1050 Brussels Belgium 00 420 224829413	Camille Latimier C.Latimier@inclusion-europe.org
EU Fundamental Rights Agency Rahlgasse 3, A-1060 Vienna, AUSTRIA tel +43-1-580 30 60 fax +43-1-580 30 693 E-mail: information@fra.europa.eu	

The Global Applied Disability Research and Information Network on Employment and Training Employment and Disability Institute Cornell University. 201L Garden Avenue, ILR Ext. Bldg. Ithaca, NY 14853-3901 Phone: (607) 254-8311 Fax: (607) 255-2763 TTY/TDD: (607) 255-2891 Email: ee224@cornell.edu	Susanne Bruyère (Director) Erika L. Eckstrom (Administrative Assistant)
European Coalition for Community Living c/o National Centre for Independent Living 4th Floor Hampton House 20 Albert Embankment London SE1 7TJ Phone: (+44 20) 7587 3982 Fax: (+44 20) 7582 2469 coordinator@community-living.info	Ines Bulic (Coordinator)
European Blind Union, 58 avenue Bosquet - 75007 Paris Tel : +33 1 47 05 38 20 Fax : +33 1 47 05 38 21 E-mail : ebuoffice@euroblind.org	
Mental Disability Advocacy Centre, Rákóczi út 27/B, 1088 Budapest, Hungary Tel: + 36 14 13 27 30 Fax: +36 14 13 27 39 Email: mdac@mdac.info	Oliver Lewis
European Disability Forum / Forum européen des personnes handicapées Rue du Commerce 39-41, 1000 Bruxelles 32 2 2865181	Carlotta Besozzi Carlotta.besozzi@edf-feph.org
Department for Work and Pensions London 020 7340 4375	Stephen Thrower Stephen.thrower@dwp.gsi.gov.uk

Equality and Human Rights Commission 3 More London Riverside Tooley Street, London, SE1 2RG	Neil Crowther, Disability Policy Neil.crowther@equalityhumanrights.com
Equality Authority 2 Clonmel Street Dublin 2 Ireland. Telephone: +353 1 4173333 Business Queries: +353 1 4173336 Email: info@equality.ie	
UK Disabled Peoples Council Derby	Simone Aspis - Development Officer
Disability Equality in Education UK	Richard Rieser r.rieser@diseed.org.uk