

Promoting inclusion?

Disabled people, legislation and public policy

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May 2005

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## Executive Summary

DAA has undertaken this research, on behalf of the Department for International Development's [DfID] Knowledge and Research Programme, to satisfy the following objectives:

1. Collaboration between representative organisations of disabled people to promote critical analysis of law, policy and its implementation (intended to have an impact beyond the limits of this project);
2. A systematic appraisal of the content and impact of disability legislation/policy on the lives of disabled people;
3. An investigation into the nature and extent of disabled people's influence on the legislative and policy process;
4. The identification of key strategies and techniques for exerting decisive influence on the legislative and policy process;
5. Elaborate the goals of policy makers and disabled people in the construction of legislation/policy, with particular emphasis on apparent synergy and/or dissonance between such goals;
6. Provide 'best practise' examples.

## Key Findings

### Generally

- The generally precarious position of disabled peoples' organisations [DPOs] in the policy process has been highlighted by the fear, expressed by a number of respondents, that candid responses to the project survey would result in recriminations.
- Any claim that disabled people are part of the policy process must be viewed in relation to such anxiety and indicates, we believe, the work still to be done to ensure the participation of this group.

### Internationally

- Effective participation at the UN requires that DPOs have relevant 'in-house' expertise (i.e. UN procedures and agencies, and international law). Few DPOs can afford such expertise and, when it is available, it is almost invariably provided, *pro bono*, by disabled people and our supporters on a part-time basis.
- The mismatch between the resources available for NGO participation, at whatever level, and that available to governments and to the various business and professional organisations increasingly active at the UN amplify the barriers to equal participation in the international community.

- The UN has tended to replicate national and regional governmental policy by relegating the expertise and contribution of disabled people, and our representative organisations, to that of ‘users’ or ‘consumers’, rather than autonomous agents capable of making an equal contribution.<sup>1</sup>

## Nationally

- There has been a welcome increase in awareness of disability as a civil rights issue by governments and policy-makers, with a concomitant growth in the enactment of legislation to protect such rights. However, it is clear that legislation is invariably inadequately funded and/or subject to ineffective monitoring and enforcement. It appears that the mechanisms that exist in the areas examined as part of this project place too much reliance on disabled people’s good will and voluntary effort.
- Although DPOs report at least some involvement in drafting legislation and influencing policy over the past 5-years, such involvement has not been given similar status to that provided by ‘professional’ agencies and is extremely weak at the local level. Governments appear to rarely acknowledge a need to resource DPO inclusion in the consultative process or to fully recognise their expertise, often preferring to listen to the voice of single impairment organisations, particularly those of parents and non-disabled professionals.
- Information is not being communicated – in either direction – from the national governmental and DPO leadership level to grass-roots organisations.
- Several countries identified the low priority given by their governments to disability rights because of general political and economic factors.
- Some examples of good practice were found, particularly in South Africa and Uganda, where disabled people play a significant role in the institutions of government and at all levels. However, even in these countries respondents felt that ‘the grass must be greener on the other side’, that is, in ‘developed’ countries, demonstrating the lack of shared information on the realities of disabled lives, worldwide.
- This lack of knowledge on the reality of disabled lives is also evident in governmental and privately funded resource programmes, where it is assumed that there is no need to support DPOs in the ‘developed’ states. Thus, we have been unable to identify a single state from whom compelling lessons could be learned.

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<sup>1</sup> For example, in a private conversation, one of the participants in the United Nations Consultative Expert Group Meeting on International Norms and Standards Relating to Disability (Convened by the United Nations in cooperation with Boalt Hall School of Law, University of California at Berkeley and the World Institute on Disability, 8-12 December 1998, at Boalt Hall School of Law, University of California at Berkeley) admitted, to one of the authors of this report, that they were so concerned about the relative invisibility of disabled people from the meeting, they considered withdrawing from it.

## RECOMMENDATIONS

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1. Disability, and programmes related to it, remain a 'special' case, that is to say legislation and public policy too often appears to proceed on a charitable or welfarist basis. This approach 'others' disabled people, replicating and reinforcing the circle of exclusion. In our view, the situation is such that, in order to recognise the inherent humanity of disabled people and their rights and protections, all legislation should operate in a **human rights dimension**.
2. We believe that there are practical and fiscal benefits that flow from disabled people's inclusion in the consultation and influence agenda, at regional, national and local levels, which can only be achieved with **formal and appropriately resourced partnerships** between governmental and DPO actors, especially at the local level.
3. A significant factor in the continued low status associated with disablement is the tendency to demean or degrade disabled people's contribution to the policy agenda. As recent research has indicated (Ásgeirsdóttir, 2003: 3 and Stapleton *et al.* 2004), the modest impact achieved by governmental disability programmes demands new paradigms and recognition of disabled people's contribution to the policy and governance process, a secondary effect of which is likely to be greater participation and inclusion, precisely the aim – if not the outcome – of existing and preceding programmes. The present **low 'glass ceiling' for disabled people must be raised** and enabling structures put in place.
4. Despite increasing legal activity in national, regional and international fora, there is **insufficient evidence concerning the reality of 'disabled lives'**. If policy is to be better directed – and practical outcomes achieved – there is a pressing need to obtain more data and/or to disaggregate data from pre-existing data sets. However, the collection and manipulation of data must not be allowed to become an end in itself or, indeed, a tactic deployed to delay effective action.
5. **Legislation must be mandatory, adequately funded and subject to enforcement mechanisms** that are accessible to disabled people and capable of imposing penalties adequate to the task of combating illegal discrimination.
6. It is increasingly clear that the '**Social Model of Disability**' lies at the foundation of disabled people's political campaigns around the world, with the result that any legislation or policy that fails to adopt a social model perspective will fail to address the expectations of disabled people.

### Introduction

The development of a politicised movement of Disabled People, beginning in the late 1960s, is marked by the demand for social justice and equal rights. As has been extensively reviewed elsewhere, the movement's greatest challenge has been to combat, at best, condescending and, at worse, unashamedly prejudiced, attitudes toward disabled people.

Though the disability movement has, demonstrably, done much to challenge traditional orthodoxies, not least by placing disability on the political agenda, empirical and anecdotal evidence suggests that such accomplishments have yet to filter down to the daily lives of the disabled population. Whilst physical and attitudinal barriers are being addressed at the systemic level, the individual experience of disability remains, for too many, marked by abuse, exclusion and deprivation.<sup>2</sup>

What is particularly perplexing about this disparity between the social and individual is that increasing numbers of states have legislated to combat discrimination against disabled people. Furthermore, just as states are increasingly acting to combat discrimination at the

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<sup>2</sup> "Abuse recorded in the Database is measured against the Universal Declaration of Human Rights, 1948 [adopted by UN General Assembly Resolution 217 A (III), 10 December 1948]. Whilst it is understood that the Universal Declaration does not provide 'justiciable rights', it provides a minimum standard against which DAA believes states should be judged.

At 19 October 2004, the database contained 2,248 cases, affecting at least 2,219,150 disabled people. It should be noted that the number of disabled people enduring human rights abuse is substantially greater, however, as victim numbers are only entered where they are quantifiable. Thus, a number of cases contained on the Database detail systemic and widespread abuse, affecting a substantial but unknown number of disabled people.

As with previous reports on the Database, the most alarming statistic concerns the number of cases resulting in the death of the victim. To date, 250 cases reveal the deaths of 305,229 disabled people as a result of human rights abuse. In line with previous findings, eleven per cent of cases recorded concern the death of the victim. A further 34% of cases are of degrading and inhuman treatment – all of them cases of incredible horror, including stoning, burning, caging, restraint, neglect and abuse of all kinds.

Despite insurmountable funding problems, the DAA Human Rights Database continues to highlight the endemic and global abuse of disabled people's human rights. Quite apart from the type and extent of abuse, the Database also stresses the paucity of academic research, as well as governmental or mainstream NGO activity in this area. Increased activity within the UN – arising from efforts to elaborate a thematic convention – do not appear to have been translated into effective action or campaigning. It can only be hoped that this failing will be addressed without further delay.

Additional comment is unnecessary; the data provided above stands as a continuing indictment of the treatment endured by disabled people [Light, R. (2004) *Summary Report of DAA's Human Rights Database*, London: DAA]."

municipal level, in 2002 the General Assembly of the United Nations acknowledged a similar disparity between theory and practice and, in consequence, voted to establish an ad hoc committee to review methods of achieving equal enjoyment of human rights at the international level.

To summarise in a way that would, we are sure, resonate with disabled people themselves, there is a substantial gap between rhetoric and reality. For thirteen years, Disability Awareness in Action [DAA] has been at the forefront of developing a disability rights discourse, principally by acting as a clearing house through which disabled people and their representative organisations, in 164 countries around the world, exchange information and expertise through a collaborative and cooperative information network.

DAA achieved this through the production and dissemination of a monthly newsletter, periodic resource and research material and regular e-mail, telephone and postal interaction. Through monitoring and evaluation questionnaires, DAA has methodically identified and explored the priorities of disabled people around the world. Without exception, policy and legislation to promote civil rights has been the issue about which disabled people express the greatest interest – and concern.

Responding to the views of its constituency, in 2001 DAA undertook research, building on our Resource Kit 7: Civil Rights Law and Disabled People, by using further evidence and examples to examine disability rights law in seven countries, in greater detail. This Cutler Report of 2001 was informative but we were not able to properly evaluate the legislative achievements or the involvement of disabled people in the process: elements crucial to enforcement of rights and social change to better ensure the inclusion of disabled people in their societies.

This KaR thematic research opportunity has allowed us to look in greater detail at the outcomes of the increasing rights legislation that is being implemented around the world and the role of DPOs in the process.

## **Objectives of the research**

At the outset, the ambitious objectives of the project were identified as:

1. Collaboration between representative organisations of disabled people to promote critical analysis of law, policy and its implementation (intended to have an impact beyond the limits of this project);
2. A systematic appraisal of the content and impact of disability legislation/policy on the lives of disabled people;
3. An investigation into the nature and extent of disabled people's influence on the legislative and policy process;
4. The identification of key strategies and techniques for exerting decisive influence on the legislative and policy process;
5. Elaborate the goals of policy makers and disabled people in the construction of legislation/policy, with particular emphasis on apparent synergy and/or dissonance between such goals;

6. Provide 'best practise' examples.

## Methodology

A key element of the research methodology was the equal participation of disabled activists in Africa, Joshua Malinga and Tomson Dube, both of whom were involved in all stages of the research process, from initial design, implementation and review. Such participation provided invaluable insights, not least in relation to reporting on informal discussion with survey respondents, which provided essential sensitivity to the 'sub-text' of responses. Whilst we carefully avoided elevating such insight to the status of empirical fact, it has informed our choice of secondary sources and, indeed, stressed the need to reinforce the data revealed by this small-scale study with such sources.

Evidence was therefore supplemented by reference to:

- DAA archives, including the Human Rights Database, policy and legislation library, disabled people's own testimonies and letters collected over the years from our readers in 164 countries.
- The lived experience of the Project Team, which includes *chairing*: Rights Now [UK], Our Rights Now [UK], Disabled Peoples' International, DPI Europe, African Decade of Disabled People and the Pan-African Decade of Disabled People; supplemented by *membership* of: The Disability Rights Task Force [UK], UK Delegation to the UN Ad Hoc Committee on ....., BCODP International Committee.
- The Cutler report (2000) which covered 11 countries: Australia, China, India, Ireland, Italy, Jordan, New Zealand, Philippines, United Kingdom, United States, Zimbabwe.
- Rights for Disabled Children/DAA research studies in Romania, South Africa, Nepal and El Salvador.
- International Disability Rights Monitor (IDRM) Compendium of rights legislation and policy in 54 countries and the IDRM Inter-American Report which had disabled researchers and covered Argentina, Bolivia, Brazil, Canada, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, El Salvador, Guatemala, Guyana, Honduras, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, Surinam, United States and Uruguay (22 countries).
- Detailed questionnaires sent to 12 countries and completed by 8 respondents in 6 countries.



### **An international perspective**

In addition to the foregoing elements of this research, this KaR project also offers the opportunity to revisit research objectives with current work at the United Nations, to elaborate a thematic convention to promote the human rights of disabled people. In passing Resolution 56/168, on a 'Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities' in 2001, the UN General Assembly was implicitly acknowledging that disabled people's equal enjoyment of internationally agreed human rights and fundamental freedoms could not be taken for granted.

In the period since adoption of Resolution 56/168, the UN Ad Hoc Committee has met on five occasions; there was also a smaller Working Group meeting, to propose draft text for a new legal instrument, in January 2004. DAA has been intimately involved in the convention process, with a senior member of staff attending all sessions of the Committee, on all but one occasion, as a member of the official UK delegation, reporting on the work of the Committee internationally and making two written submissions to the Committee. We feel, therefore, that it is appropriate – if not essential – to refer to the UN process in this report.<sup>3</sup>

### **Ensuring that the voice of disabled people is heard**

Of the seven international non-governmental organisations with consultative status with the UN's Economic and Social Committee (collectively described as the 'International Disability Alliance') just one: Rehabilitation International, has an office in New York – where the UN is headquartered – and none have offices in Geneva, where the High Commissioner for Human Rights is based and the Human Rights Committee meets. Accordingly, it will be readily understood that INGO participation in the UN's human rights activity has significant resource implications for disabled peoples' organisations [DPOs].

Furthermore, effective participation at the UN realistically demands in-house expertise on UN procedures and agencies, and international law. Even where such expertise might be available, it comes at a price that few DPOs can afford; accordingly, such expertise is usually provided, *pro bono* by disabled people and our supporters on a part-time basis.

The mismatch between the resources available for NGO participation, at whatever level, and that available to governments – all of whom maintain permanent missions in New York – and to the various business and professional organisations increasingly active at the UN amplify the barriers to equal participation in the international community.

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<sup>3</sup> It must, of course, be acknowledged that the observations provided are the subjective account of an individual but, importantly, that individual is a professionally trained and qualified academic researcher.

Although difficult to quantify but, we believe, no less pertinent, the UN has tended to replicate national and regional governmental policy by diminishing the expertise and contribution of disabled people, and our representative organisations, to that of ‘users’ or ‘consumers’, rather than autonomous agents with an equal contribution to make.

## The National Perspective

Before moving to the substantive issues highlighted by the research, it is sobering to note, in a study directed at disabled people’s participation in the policy process, that the majority of respondents expressed concern about the risk of repercussions were they to be critical of their government.

Unsurprisingly, respondents expressed little desire to discuss the nature of such repercussions, not least whether such consequences would attach to them or to the organisations they represent. To a large extent, we consider this distinction to be of limited practical import: that respondents feared *any* punitive response to their candour is, we believe, a critical research outcome in and of itself.

What is, perhaps, more alarming still, is that reprisal for ‘upsetting the apple cart’ has been a common theme in the routine work of DAA: from ‘disappearances’ in Latin America<sup>4</sup> to exposure to administrative processes linked to the receipt of welfare benefits. In all cases, the clear signal that advocacy risks punishment is communicated. Such oppression comports with the way in which government goes about the routine business of governance in some states but, before dismissing the problem as a regional anomaly, we believe that it is important that it is acknowledged that pre-existing evidence shows similar vindictiveness in states that make much of their status as ‘liberal democracies’.

In addition to suggesting that disabled people’s involvement in the policy process is both fragile and conditional, such concerns go to the very heart of civil and political rights ostensibly protected by international and regional human rights instruments. Although arguably tangential to the aims of this study, we believe that governmental support for effective advocacy by disabled people’s organisations would provide a meaningful indicator of democratic engagement as well as ensuring, as is done in the political systems in South Africa and Uganda, that disabled people play a substantive role in the political processes of government.

Findings from all our research show that, despite efforts at the international<sup>5</sup> and national levels, there has been modest impact on the lives of disabled people. Repeatedly, disabled people identify the causes of this failure with reference to the fact that legislation is either not mandatory, has no – or inadequate – penalties attached or has no – or ineffective – enforcement mechanisms. Further, disabled people believe that national

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<sup>4</sup> DAA HR Database.

<sup>5</sup> Including the UN Disability programmes: the World Programme of Action, the UN Standard Rules, the Human Rights instruments and now the elaboration of convention to better protect the human rights of disabled people

legislation is passed without adequate resources being allocated for its implementation and that reform is, too often, premised on DPOs voluntary endeavours.

Whilst judicial review is available, in specific circumstances, to disabled people in Australia, Canada, France, Germany, Israel, UK and the Czech Republic, and Commissions concerned with disability rights or equality in the UK, USA, Australia, South Africa and Canada, respondents to this study highlight the inaccessibility of such rights to ordinary disabled people. In rural or poor districts of urban areas, in particular, disabled people have little or no awareness of their rights, or knowledge of sources of advice or funding to launch action against alleged discriminators.

Enacting legislation or creating review and enforcement bodies that are inaccessible to disabled people is impossible to reconcile with a commitment to social justice and inclusion.

Such findings do not merely reveal a failure by governmental agencies, but by mainstream NGOs and advice centres, DPOs and the media. Without the active support and involvement of each of these groups, the situation is unlikely to improve, not least because this systemic failure goes entirely unreported and unchallenged.

### **Collaboration between representative organisations of disabled people to promote critical analysis of law, policy and its implementation**

#### **Internationally**

As was identified earlier (page 4, above), undertaking critical analysis of law and policy presumes at least a minimum level of technical knowledge but, if such analysis is to be undertaken in relation to disability, it is clear that pre-existing assumptions of what amounts to expertise, and by whom it may be provided, needs to be re-examined. The UN makes regular use of 'established experts in the field' and, as meetings immediately prior to the Ad Hoc Committee process attest, disabled people do not feature in that list of experts. Nonetheless, the need to elaborate a new thematic convention in the manner adopted indicates the need to look elsewhere for guidance.

Sending representatives to New York for sessions of the Ad Hoc Committee imposes a substantial burden on DPOs but, nevertheless, such representation has grown, exponentially, since the First Session, such that by January 2005, the UN had received in excess of 500 applications from NGOs seeking to send an accredited representative to the Committee.

Despite the difficulties associated with collaborative working at the Committee,<sup>6</sup> NGOs have made a substantial contribution to the process. Although the heterogeneity of the disabled community is rarely acknowledged in public policy, to say nothing of the regional and cultural diversity of an international movement of disabled people, DPOs have shown

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<sup>6</sup> Including availability of rooms, office equipment and supplies, finding the time to adequately debate issues outside the formal sessions and ensuring that such meetings are accessible to all participants.

that collaborative working can and does produce critical analysis of governmental proposals.

As a result of the work of DPOs at the UN, not only has the scope and content of the draft convention been substantially changed to reflect the views and aspirations of disabled people, the process has demonstrably:

1. Increased disability awareness in states across the globe;
2. Served to counter ignorance, prejudice and benign neglect amongst policy-makers and diplomats involved in the process;<sup>7</sup>
3. Promoted a thoroughgoing review of accessibility to buildings, information and programmes at the UN, and
4. Contributed to the process of 'mainstreaming' disability in public policy.<sup>8</sup>

Impressive though the collaborative accomplishment of DPOs has been, it is sobering to consider how much more easily such outcomes might have been achieved with access to greater resources.

### **Nationally**

As we have already reported (see page 13, above), in some states fear of repercussions inhibits disabled people from participating in the policy process. The power imbalances that operate between marginalized groups and those in authority are also a significant factor in the consultation and influence process. Such power imbalance is further impacted by the following factors:

- DPOs have inadequate funding to travel to, and be part of, the consultative mechanisms; governments and policy-makers rarely accept responsibility for funding their participation<sup>9</sup>.
- As an evaluation of the African Decade noted, information is not passing from national leaders to grassroots organisations, nor are grassroots organisations involved in representation at the national level. The Internet has certainly widened opportunities but is not available to most disabled people in the developing world

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<sup>7</sup> It should be remembered that the impact of the process on government departments extends far beyond the individuals attending the Committee, few of whom will not have had detailed instructions from their capitals, with contributions from the various administrative departments thought to be affected by any subsequent convention.

<sup>8</sup> There is neither time nor data to critically assess the extent to which 'mainstreaming' has infiltrated day-to-day work at the UN, but it is clear that the matter is now 'on the agenda'.

<sup>9</sup> Further evidence of such difficulties is provided by personal experience amongst the research team: one of the authors of this report, as a recognised expert on bioethics, is routinely invited to attend meetings of the International Bioethics Committee of UNESCO. Despite the relevance of the Committee's work to disabled people, such invitations are limited to acting as an 'observer', rather than a contributor and have never been accompanied by the offer to fund travel and accommodation to the various glamorous international destinations favoured by the Committee.

and national DPOs are not prioritising the translation of information into accessible formats, languages and presentations. Again, this is not primarily due to lack of will, but lack of resources.

## **A systematic appraisal of the content and impact of disability legislation/policy on the lives of disabled people;**

### **Internationally**

Perhaps the greatest achievement of the DPOs directly engaged in the work of the Ad Hoc Committee has been in sharing information, advice and opinion through wide-ranging discussion, much of it through a web-based discussion group. As even the most cursory review of that discussion group will confirm, the contribution of activists, advocates and lawyers across the world has served to highlight the impact of textual proposals on disabled people.

It must be acknowledged that web-based discussion is far from ideal, not least because of the exclusion of grassroots organisations and individuals in the majority world, where access to a telephone, much less the internet, is not locally available and, it appears that the DPOs have, themselves, acknowledged such difficulties. Nonetheless, it is abundantly clear that the Internet provides a cost-effective way for *some* of the international community to take an active role in the process.

Although, perhaps inevitably, the internet-based discussion is most vigorous between meetings of the Ad Hoc Committee, the Internet has also been used extensively to provide daily briefings on the work of the Committee and the concerns of the DPOs present,<sup>10</sup> so that progress is monitored, globally, in 'real-time'.

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<sup>10</sup> It would also appear that, without the immediate communication available via the internet, efforts to elaborate a convention would have been frustrated at the First Session of the Committee in 2003. Fears that some states were pushing to abandon the Ad Hoc Committee, activists across the globe were asked to contact their government and politicians and voice their opposition to such tactics. Coincidentally or otherwise, the First Session did proceed and continued more positively thereafter.

Acknowledging that there are still barriers to address, progress at the UN indicates that the Internet can provide an inexpensive and generally effective means to promote the inclusion and participation of disabled people. In this regard, it would certainly appear helpful to explore means of promoting 'virtual international communities' and, in the particular case of disabled people, such technology offers the potential of greater engagement with the international community than is physically possible with the individual's local community. The converse is equally relevant, however: denying disabled people access to communication technology exacerbates their exclusion from the mainstream.

## **Nationally**

Most countries have multiple statutory enactments that deal with different aspects of disability rights. Some are based on a holistic constitution, though these constitutions do not always name disabled people as a specific group – a reflection of the UN human rights instruments. How the legislation or policy is produced varies but does not seem to have any impact on outcomes: disabled people are still systematically being denied their rights in every country in the world. The important improvement is that, in those countries where their rights are properly protected, disabled people do have an opportunity, however great the economic and social barriers, to be seen as equal and participating citizens.

The *International Disability Rights Monitor Regional Report of the Americas* is particularly interesting as the majority of the researchers were local disabled leaders who were able to contribute their own perspective. Overall legal protections in the region are good, influenced in the main by the Organization of American States' (OAS) Inter-American Convention On The Elimination Of All Forms Of Discrimination Against Persons With Disabilities, (June 1999) which compelled the creation of at least some disability legislation through the ratification process.<sup>11</sup> By protecting disabled people under international law, the convention is an important regional instrument for the protection of disability rights.

In addition to international law, the national constitutions of half the countries in the region specifically identify disabled people as the subjects of rights. Fourteen countries have passed additional laws that deal solely with protections, and most others include disability issues within other types of legislation. Canada, Chile, Costa Rica, Dominican Republic, Ecuador, Panama, Uruguay, and the United States all have anti-discrimination legislation.

However, the researchers often identified a reliance on charity rather than rights and most of the legislation lacks enforcement procedures.

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<sup>11</sup> Article III of the Convention affirms that: "To achieve the objectives of this Convention, the states parties undertake: 1. To adopt the legislative, social, educational, labor-related, or any other measures needed to eliminate discrimination against persons with disabilities and to promote their full integration into society..."

Of the 34 States that could have ratified the Convention, only 15 have done so [<http://www.oas.org/juridico/english/ga-res99/eres1608.htm>, checked on Thursday, May 26, 2005].

Some disabled people are stripped of the right to vote, as well as a host of other rights, in this manner. Argentina, Bolivia, Peru, and Uruguay classify people who are deaf and cannot speak as legally incapable. People with intellectual impairments can have their rights taken away in Brazil, El Salvador, Guyana, Jamaica, and Peru. People with a sensory disability, such as blind people, may face such treatment in El Salvador, Guatemala, and Guyana. Finally, Canada reports that disabled people whose health represents a potential financial burden to the state may not be allowed to immigrate.

## **An investigation into the nature and extent of disabled people's influence on the legislative and policy process**

### **Internationally**

Constraints of format and resources, to say nothing of ongoing effort at the UN, frustrate authoritative investigation of the nature and extent of disabled people's influence on the legislative and policy process. However, as we hope the foregoing makes clear, there is much about disabled people's influence on the UN process that demands detailed investigation.

It would appear disabled people have exerted influence by:

- Lobbying national governments and regional governmental organisations including, for example, the European Union.
- Lobbying delegations and Permanent Missions to the UN.
- Finding and building consensus with national and regional representatives by emphasising pragmatic matters of shared concern including, for example, the impact of poverty in the creation and perpetuation of disablement and equitable access to resources, including development programmes and healthcare.
- Responding to theoretical dialogues by 'humanising' the subject. Thus discussion of involuntary institutionalisation or treatment has been informed by the often harrowing testimony of psychiatric survivors; the reality of 'warehousing' people with learning difficulties by the heartfelt and compelling testimony of representatives from that community.
- Taking responsibility for correcting inaccurate assumptions, ignorance or prejudice – much time and effort has been devoted to explaining why the views expressed by some governments do not comport with those of disabled people. Rather than being forced into gainsaying and conflict, the close collaboration of DPOs and civil servants has enabled informal discussion of problematic areas; put simply, it is difficult to dismiss the expectations of disabled people when one then has to stand next to them in a lift or at the coffee bar. Maintaining close proximity during two-week sessions appears to make it harder for inflexible positions to be maintained against the views of civil society.

### **Nationally**

The countries that responded to our questionnaire were at very different stages of the struggle for disability rights and the responses reflected their expectations and belief in what amounted to good practice. South Africa's response, in particular was surprisingly

negative, though they also showed that their expectations were much higher and they were more aware of what was possible.

All responses to our questionnaires identified a good or excellent relationship at ministerial level but that was infrequently maintained with civil servants and rarely occurred at local level. However this good relationship was not reflected in how they answered the other questions – except for Kenya and South Africa - they did not feel that they had really been listened to or their views taken properly into account. They all had serious concerns as to the non-implementation of the legislation and Nepal and Bangladesh both identified party-political tensions as a barrier.

One of the issues that came out of the Inter Americas report is that when a single-impairment group took the leadership in consultation and influence, that impairment was the only one properly reflected in the ensuing policy/legislation.

It was clear from all our research that disabled people's general status is low and that, even when supported by evidence of violations, their arguments are not given the credibility they should as coming from experts in disability rights. It is only when they hold the same politically powerful positions as non-disabled people that their expertise is fully recognised and considered (South Africa and Uganda). Several countries in South America reported that parents and charitable or rehabilitation organisations led by non-disabled people were more likely to be listened to than disabled people, something that would, we are sure, resonate with DPOs in other regions.

## **The identification of key strategies and techniques for exerting decisive influence on the legislative and policy process**

### **Internationally**

We must be cautious about extrapolating strategies from an international process and suggesting that they are easily transferable to national policy-making. Rather than governmental actors being able to impose domestic priorities or programmes on the international community, the very nature of debate at the UN requires accord across national and political divides.

Nonetheless, there are some key points that ought, we feel, to be made:

### **Promoting conciliation**

Although sometimes acknowledged, experience at the UN and elsewhere suggests that the challenges posed by the sometimes conflicting needs of disabled people are rarely addressed. The search for quick answers tends to impede, rather than promote, conciliation between the diverse individuals comprising the disabled community. One of the key strategies of DPOs in New York has, without doubt, been the substantial investment in ensuring discussion between impairment-specific and regional DPOs.



Where governments are committed to allowing disabled people space to contribute to policy and legislative development. Resources and support<sup>12</sup> need to be allocated for diverse groups to seek common ground. This does not mean, nor should it, that there can be a single, unified view, but it does allow for the promotion of compromise solutions that benefit the greatest number, rather than favouring one group at the expense of another.

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<sup>12</sup> For example, relevant documentation provided in accessible formats and in plenty of time for NGOs, many of which will be administered by part-time volunteers, to review, discuss and comprehend the material; meeting rooms, travelling expenses and personal assistance/interpretation.

## Entering and supporting dialogue

We believe that it is essential for law and policy makers to enter into a dialogue with DPOs, who are treated as equal participants and contributors in an ongoing process. In the particular circumstances of the UN Ad Hoc Committee, there has been substantial continuity in delegations from member states and NGOs, such that relationships of trust and respect are fostered; although there remains an element of 'us' and 'them', we believe that positive collaboration and frank dialogue has been a hallmark of the UN process. It must be acknowledged that this scenario has been hard-won and, as subsequent sessions may prove, contested.

### Nationally

It has proven difficult to identify the particular strategies and techniques that have been most successful in influencing policy-development at the national level. However, the evidence shows that there are several strategies that have to be in place to be truly effective and that these are a reflection of, and build on, those strategies needed at the international level:

- A formal process for consultation, including full and equal membership of DPOs on governmental advisory/consultative groups.
- Legislative and policy objectives need to be based on respect for human rights, non-discrimination and the right to appropriate services and protections for all disabled people, regardless of impairment. These objectives need to be implemented in social security and service provision legislation, just as much as in overall human rights and non-discrimination legislation.
- Disabled people must form the majority in enforcement and monitoring mechanisms, including commissions, boards and ombuds offices.
- All these mechanisms and legislative implementation require adequate funding. It was quite clear from the IDRM report that most of the enforcement mechanisms were not working because of lack of status and funding. Whereas both South Africa and Uganda, which have disabled people in positions of authority and political power at all levels, have a greater chance of implementation of their legislation. In Uganda particularly, because there are locally appointed disabled people among the village elders as well as disabled political representatives at every other level, the status of disabled people has changed dramatically. (Dube, 2005 p.54,55)
- Evidence of the need for legislation and, importantly, the cost-effectiveness of non-discrimination and the protection of rights are crucial elements of the debate. These arguments have been proved in relation to other marginalized groups, particularly women, but disabled people are seen as too expensive and too difficult to include in mainstream society. These cost arguments have been effectively denied by Wolfensohn and Sen in relation to the poverty eradication agenda and the Millenium Development Goals and should be used in relation to legislation and policy.

## **Synergy of Goals**

### **Elaborate the goals of policy makers and disabled people in the construction of legislation/policy, with particular emphasis on apparent synergy and/or dissonance between such goals**

Failure to reach a common understanding of what is possible and permissible can frustrate synergy and care needs to be taken in attributing motives or causes to a failure to agree legal or policy objectives. Nonetheless, there is cause to believe that policy makers and disabled people approach the subject from differing starting points and with very different goals.

To take employment as an example, few DPOs would now advance an appeal for equal employment opportunity in isolation, viewing such opportunity as one part in a larger complex of issues and challenges. The risk in emphasising greater employment is that DPOs can find the argument turned around to justify regressive welfare-to-work programmes.

It is also, we believe, important to note the views of disabled respondents to the survey circulated in this research: that legislation appears to be viewed as an end in itself by policy-makers, whereas disabled people increasingly view legislation as one part in a wider programme. This is particularly striking in view of the feeling that legislation rarely provides for effective individual remedy or adequate funding for advisory and implementation services. Such factors have also been evident at the UN, where member states are relatively willing to provide rhetorical support for disabled people's human rights, but appear unwilling to underwrite the cost of making such equality a reality.

However much governments speak the language of 'rights' in relation to disabled people they did not, in most cases, support disabled people in playing an appropriate role in the political process and disabled people were likely to agree compromise decisions because of the imbalance of power between DPOs and government.

## **Best Practise**

We believe that foregoing discussion illuminates best practise in a number of vital areas. The UN Ad Hoc Committee, particularly in the context of traditional UN procedures, has made outstanding efforts to ensure the effective, if not entirely equal, participation of DPOs. More importantly, the demonstrable influence of DPOs on the content and progress of the draft convention illustrates the mutual benefits of promoting such participation.

That disablement is created and perpetuated by the failure to understand what might, perhaps inappropriately, be described as a 'disability perspective' has become something of an orthodoxy within the politicised disability movement. Best practise in relation to disablement must, therefore, permit disabled people to elaborate, both privately and

publicly, what it means to be disabled: to move the discourse from the hypothetical or theoretical to the practical and conceptual.

Because overall progress in promoting rights for disabled people has been slow, despite some progressive and comprehensive legislation, this project has tended to provide ample examples of pitfalls to avoid, rather than best practise to follow. Below are some examples of good practise that appear necessary if there is to be any real progress:

- Some of the South American states (Bolivia, Costa Rica, El Salvador, Guyana,) had offices that were collecting evidence on violations of civil and human rights against disabled individuals. This data was used as a campaigning tool for ensuring effective legislation and services. Additionally, data from the DAA Human Rights Database added impetus to the initial stages of the elaboration of a convention on the rights of disabled persons.
- Legislation that creates enforceable obligations, backed up by vigorous and accessible implementation and, where necessary, reinforced by penalties sufficient to promote compliance. Even where these are in place, many disabled people do not know of their rights or how to access them. As Canada and the UK have found, commissions dealing with enforcement of non-discrimination have inadequate resources to administer all complaints and have to prioritise their work. Nevertheless, these essential ingredients of enforcement did make a substantial difference to the efficacy of the legislation.
- A Social Model definition of disability, as appears in the legislation of South Africa, the Philippines and Zimbabwe, has addressed the problem of defining the protected class restrictively, thereby leaving disabled people without protection or remedy. The Inter-American Convention also has a Social Model component,<sup>13</sup> emphasising the need for social change in place of charitable attitudes or compensatory policies.
- The concept of reasonable accommodation or adjustment (UK, USA, Canada, Australia) is increasingly being used as the most effective means of promoting accessibility – in its widest sense – and is supported by disabled people as being essential if there is to be real social change.<sup>14</sup>
- South Africa and Uganda provide compelling evidence of the benefits of disabled people's inclusion in national politics and the policy-making agenda. However, in both countries there is evidence to suggest that such political involvement can cause tension between the democratic movement of disabled people and the disabled individuals in the government. Further research is necessary to establish whether there are lessons of general applicability available in South Africa and Uganda.

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<sup>13</sup> *'The term 'disability' means a physical, mental or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities of daily life and which can be caused or aggravated by the economic and social environment.'*

<sup>14</sup> Evidence the importance attached to this concept in debate at the UN Ad Hoc Committee, for example.



## APPENDIX 1

### EDITED SURVEY RESPONSES<sup>15</sup>

1. In the last 5-years, has your government introduced any national legislation or policy that affects disabled people?

<b>Respondent region</b>	<b>(a) Right not to be discriminated against?</b>	<b>(b) Social inclusion?</b>	<b>(c) Social and/or political participation?</b>
<b>Melanesia</b>	Yes	No	No
<b>Southern Asia</b>	Yes	Yes	No
<b>Southern Africa (a)</b>	Yes	Yes	No response
<b>Southern Africa (b)</b>	No	No	No
<b>Eastern Africa (a)</b>	Yes	Yes	No
<b>Eastern Africa (b)</b>	Yes	Yes	No response
<b>Eastern Africa (c)</b>	No	Yes?	No response
<b>Eastern Africa (d)</b>	No	No	No

2. For each law or policy please answer the following questions:

<b>Respondent region</b>	<b>(a) Was your organisation involved drafting the law or policy?</b>	<b>(b) Please describe how your organisation became involved</b>
<b>Melanesia</b>	No	Public Submission
<b>Southern Asia</b>	Yes	Public Submission
<b>Southern Africa (a)</b>	Yes	Contributed to drafting of legislation with financial assistance from overseas
<b>Southern Africa</b>	1992	Not applicable

<sup>15</sup> Responses had to be edited as some respondents refused to cooperate unless anonymity could be guaranteed. Accordingly, where the level of information provided makes identification likely, it has been removed or reduced in this summary.

<b>(b)</b>		
<b>Eastern Africa (a)</b>	Yes	Campaigning
<b>Eastern Africa (b)</b>	Yes	Member of project team
<b>Eastern Africa (c)</b>	Yes	Contributed to drafting of legislation
<b>Eastern Africa (d)</b>	Yes	Legislation passed previous decade: contributed to drafting of legislation

2. (d) At what level in your country's policy-making process was your organisation involved (please tick all that apply)?

<b>Respondent region</b>	<b>Ministerial</b>	<b>Senior civil servants</b>	<b>Junior civil servants</b>	<b>Consultants</b>	<b>Letter, phone, e-mail</b>
<b>Melanesia</b>	Yes	Yes	No	No	No
<b>Southern Asia</b>	Yes	Yes			Yes
<b>Southern Africa (a)</b>				Yes	
<b>Southern Africa (b)</b>	-	-	-	-	-
<b>Eastern Africa (a)</b>	-	-	-	-	-
<b>Eastern Africa (b)</b>	Yes	Yes	Yes	Yes	No
<b>Eastern Africa (c)</b>	Yes	Yes	Yes	Yes	-
<b>Eastern Africa (d)</b>	Yes	Yes	Yes	Yes	No

\* Also at the community level

3. Have you or any other disability organisation been involved in the discussions regarding poverty alleviation programmes (PRSPs) and/or discussions with the World Bank?

<b>Respondent region</b>	<b>Yes/no</b>	<b>If yes, please briefly outline that involvement here:</b>
<b>Melanesia</b>	No	-
<b>Southern Asia</b>	No	-
<b>Southern Africa (a)</b>	Yes	?
<b>Southern Africa (b)</b>	Yes	Strong advocacy and campaigning has not led to adequate DPO representation.
<b>Eastern Africa (a)</b>	Yes	-

<b>Eastern Africa (b)</b>	No	-
<b>Eastern Africa (c)</b>	Yes	Drought relief and poverty alleviation programmes include appointment of special officers to ensure inclusion of people with disabilities; UNDP's survey on effects of Structural Adjustment Programmes (SAPs).
<b>Eastern Africa (d)</b>	No	-

4. How would you describe the nature of your organisation's relationship with government and policy-makers?

<b>Respondent region</b>	(a) National government	(b) Civil servants	(c) Local or state government	(d) Any regional governmental organisation
<b>Melanesia</b>	Excellent	None	None	None
<b>Southern Asia</b>	Good	Good	Poor	None
<b>Southern Africa (a)</b>	Good	Poor to fair	Poor	None
<b>Southern Africa (b)</b>	Poor	Very poor	Good	Good
<b>Eastern Africa (a)</b>	Good	Good	Good	Good
<b>Eastern Africa (b)</b>	Good	Poor	Good	Good
<b>Eastern Africa (c)</b>	Good	Poor	Poor	Good
<b>Eastern Africa (d)</b>	Good	Poor	None	None

4. (e) International governmental agencies

<b>Respondent region</b>	<b>Excellent</b>	<b>Good</b>	<b>Poor</b>	<b>Very poor</b>	<b>Other</b>
<b>Melanesia</b>					We have no relationship
<b>Southern Asia</b>				Yes	There have been various programs related with human rights and good governance, but none include PWDs. Actively advocating for past 5 years, but PWD are ignored.  Beginning work with international organizations working with PWDS, e.g. Action AID, Danish development organization, MS Southern Asia,



				IMPACT UK, HANDICAP INTERNATIONAL No UN or multilateral organization or company
<b>Southern Africa (a)</b>			Yes	Other organizational and institutionalised forums such as the Disability Convention (Africa Region Presidency), not good and/or not poor.
<b>Southern Africa (b)</b>		Yes		UN agency supporting a project for the economic empowerment of women with disabilities.
<b>Eastern Africa (a)</b>				We have no relationship
<b>Eastern Africa (b)</b>			Yes	
<b>Eastern Africa (c)</b>		Yes		
<b>Eastern Africa (d)</b>				No relationship – grassroots organisation

5. Are there examples where consultation with your national government has led to your ideas being included in their projects or programmes (please provide a brief summary)?

<b>Respondent region</b>	<b>Yes/no</b>
<b>Melanesia</b>	Yes
<b>Southern Asia</b>	Yes
<b>Southern Africa (a)</b>	Yes
<b>Southern Africa (b)</b>	Yes
<b>Eastern Africa (a)</b>	Yes
<b>Eastern Africa (b)</b>	Yes
<b>Eastern Africa (c)</b>	
<b>Eastern Africa (d)</b>	Yes

6. Is there a formal system for regular meetings with the government?

<b>Respondent region</b>	<b>Yes/no</b>	<b>If 'yes', please provide a short description:</b>
<b>Melanesia</b>	Yes	Forum meets bi-monthly, comprising DPOs and government representatives.
<b>Southern Asia</b>	Yes	Government beginning to consult with PWDs organizations, particularly in relation to social welfare and education, but not formalised.
<b>Southern Africa (a)</b>	Yes	Regular meetings with the President's Office.
<b>Southern Africa (b)</b>	No	
<b>Eastern Africa (a)</b>	No	Informal meetings sought where considered necessary by DPO.

<b>Eastern Africa (b)</b>	No	Informal meetings sought where considered necessary by DPO.
<b>Eastern Africa (c)</b>	Yes	National Disability Board - chairperson and the majority of the members disabled. The board gets reports from all ministries and from DPOs that they deliberate after every three months. There is a secretariat that does the day to day running of the activities of the Board. The deliberations are taken to the minister responsible who in turn prepares a report for the Cabinet with recommendations.
<b>Eastern Africa (d)</b>	Yes	Disability Board. Lack of funding prevents smooth flow of information.

7. If you answered 'yes' to Question 6., do those meetings show evidence that your ideas have influenced government policy?

<b>Respondent region</b>	<b>Yes/no</b>
<b>Melanesia</b>	Yes
<b>Southern Asia</b>	Yes
<b>Southern Africa (a)</b>	Yes
<b>Southern Africa (b)</b>	n/a
<b>Eastern Africa (a)</b>	No response
<b>Eastern Africa (b)</b>	Yes
<b>Eastern Africa (c)</b>	Yes
<b>Eastern Africa (d)</b>	Yes

8. Is there an enforcement and/or monitoring mechanism for legislation and policy affecting disabled people? If so, please describe it?

<b>Respondent region</b>	<b>Yes/no</b>	<b>If 'yes', please provide a short description:</b>
<b>Melanesia</b>	Yes	Human Rights Commission
<b>Southern Asia</b>	No	-
<b>Southern Africa (a)</b>	No	As of now, there are no enforcements. The Government is trying by way of dangling a carrot as it were. It remains the responsibility of people with disability. It is all about creating capacity, if we did not, it falls away. With regards to social security, disability grants, we have to go the legal way: e.g. taking the government to court in order to address some issues. These efforts were accomplished through advocacy.
<b>Southern Africa (b)</b>	Yes	Relevant legislation contains non-discrimination clause, particularly in terms of access to public buildings and amenities. If there is any one e.g. public building if found an adjustment order would be issued to force the owner of the building to make the necessary adjustment and make the public building accessible. There is a Disability Board that monitors and is supposedly to monitor these irregularities. The Act provides for penalties if the owner does not comply. The fines are paltry according to current value of the money.
<b>Eastern Africa (a)</b>	Yes	The National Council for persons with disabilities which is being set up to enforce implementation of disability legislation.
<b>Eastern Africa (b)</b>	Yes	Since the policy has been recently adopted, there is not much ground that has been covered but, working on legislation has been our priority. We have been working on legislation that is supportive. There is a National Coordinating Committee, established three years ago but very dormant. It comprises different cabinet ministries, disability sector that is supposed to

		monitor policy and any proposed legislation for and/or by DPOs, that are also represented in the committee.
<b>Eastern Africa (c)</b>	Yes	The Disability Board through the Minister and the Office of the President and Cabinet is the monitoring as well as the enforcer - the Board.
<b>Eastern Africa (d)</b>	Yes	The policy is there but the mechanism is missing because what is supposed to be done is done haphazardly.

9. Are there representatives from disabled peoples' organisations on the enforcement or monitoring body?

<b>Respondent region</b>	<b>Yes/no</b>	<b>Proportion of disabled people</b>
<b>Melanesia</b>	No	-
<b>Southern Asia</b>	No	
<b>Southern Africa (a)</b>	?	?
<b>Southern Africa (b)</b>	Yes	66%
<b>Eastern Africa (a)</b>	Yes	75%
<b>Eastern Africa (b)</b>	Yes	25%
<b>Eastern Africa (c)</b>	Yes	70%
<b>Eastern Africa (d)</b>	No comment	-

10. When reviewing legislation and/or government policy introduced over the past 5-years, in your opinion, was it a response to what disabled people wanted or simply what the government wanted?

<b>Respondent region</b>	<b>Response</b>
<b>Melanesia</b>	No review done yet
<b>Southern Asia</b>	Yes they take our voice and suggestion but they do not implement
<b>Southern Africa (a)</b>	It is a little bit of both. Government looked at self over the past ten-year process. DPO assessed the years as to the integration of issues of people with disabilities. In some situations, there was collaboration with us in areas of Education, Employment, Social security and transport. DPO then assess the ministries at the provincial level.
<b>Southern Africa (b)</b>	-
<b>Eastern Africa (a)</b>	It is what disabled people wanted but the government is too slow in implementing the legislation. Persons with disabilities in [state] feel it is the basis upon which their rights can be actuated.
<b>Eastern Africa (b)</b>	There have been no policies before. Due to lobbying and advocacy by DPOs, we would like to believe that the current legislation was formed as a result of the current efforts by the said institutions.
<b>Eastern Africa (c)</b>	What the disabled people wanted. There is a powerful lobby and advocacy group that is constantly giving pressure to the government.
<b>Eastern Africa (d)</b>	We would like to believe that policy followed as a result of lobbying by DPOs.

11. Do you sense that the goals of the government are as accommodative as or similar to those of disabled people and their representative organisations (please describe)?

<b>Respondent region</b>	<b>Response</b>
<b>Melanesia</b>	This current Government has demonstrated its commitment and sensitivity to the concerns of disabled persons.
<b>Southern Asia</b>	No
<b>Southern Africa (a)</b>	Yes. However, when implemented, they shift goal posts. For example, the assessment tool' the government was not prepared to put more resources in the formulation. At the end of implementation, when assessed, the goals are not met and this is when the problem arises. It is also when we realise that certain facets were not followed. The government then advise that it was due to resources that led to the inability of unachieved goals.
<b>Southern Africa (b)</b>	In my view, the goals of the government are good. The issues of disability were discussed quite early at Independence and they are good intentions, but they tend to deteriorate. They are in line with the thinking of people with disability.
<b>Eastern Africa (a)</b>	Yes and this is manifested by various Acts.
<b>Eastern Africa (b)</b>	[State]) has been in the doldrums of all these issues for disabled people. DPO was only formed in 1999 and since then the Government had no interest in issues of disability. I would be accurate if I said that the government has no plans for DPOs, but however, the government had over the years established even against the will of people living with disabilities, community based rehabilitation and vocational training. DPO became involved in these initiatives as a way to gain a foot-hole.
<b>Eastern Africa (c)</b>	NO. We are always the last to be considered and first to be thrown out of any system if there is a problem. E.g. women have been given a quarter system in the political and government system including parliament. This system has not been extended to people with disabilities.
<b>Eastern Africa (d)</b>	There are not accommodative. We as DPOs wanted parliamentary representatives, this was not heeded to or let alone responded to. People with disabilities have tried through own (personal) initiatives but such efforts have not been supported or accommodated.

12. If you feel that the government's goals are unaccommodative or different to those of disabled people, do you have an opinion about what the government's goals were (to reduce public spending, party political objectives, to conform to an international trade or loan agreement, for example).

<b>Respondent region</b>	<b>Yes/no</b>	<b>If 'yes', please summarise what you think those goals are:</b>
<b>Melanesia</b>	No response	
<b>Southern Asia</b>	No response	Now Our government is more concern with political agenda. Social agenda is becoming minority. I don't think so in future?
<b>Southern Africa (a)</b>		The plan by the government is a noble one. There is a problem in competing for resources. No resources for disabled people. Sincerely, they want to do, they have good intentions. There is always a total shift from government level. For instance, the government sometimes insists on the medical model when dealing with people with disabilities while we advocate for the social model. In some cases they move with us. Those goals have not changed for us. We will work at empowering the disabled and many other issues. We would continue to fight for the employment of people with disabilities at key positions. All what lacks is the financial muscle and commitment from the government.
<b>Southern Africa (b)</b>		Positive efforts in the 1990s have since been reversed.
<b>Eastern Africa (a)</b>	No	-
<b>Eastern Africa (b)</b>	?	I have not the slightest idea of any of the ideas of the government.
<b>Eastern Africa (c)</b>	?	Disability is something that is difficult for govt, the public and politicians to understand. It is a complicated issue, a complicated struggle, where schools of thought including traditional Human Rights Activists fail to understand that Disability is a political, social, economic, human rights and cross cutting development issue. Disability is always seen as charity and welfare issue. But there is a strong disability voice in Eastern Africa and have made some headway.
<b>Eastern Africa (d)</b>	No	They have no goals at all for people with disabilities. If they have, we should be collaborating in many areas, but this is the missing link. The goals that are known are from DPOs. The government has never shown any action plan to show their commitment. If this is there it has not been shared or disseminated





13. Has legislation or policy introduced in the last 5-years made a positive difference to the lives of disabled people?

<b>Respondent region</b>	<b>Yes/no</b>	<b>If 'yes', please provide a short description of how:</b>
<b>Melanesia</b>	Yes	Greater awareness of the rights and potentials of disabled persons amongst members of the public.
<b>Southern Asia</b>	No	-
<b>Southern Africa (a)</b>		This question has a yes/no answer. Currently, there are more disabled people that could fly in an aeroplane than before. A relative number participate in employment, education (children of people with disability, whether themselves disabled or not disabled the children are in school. There are also in competitive schools. In the rural areas, the person would say no to this question. There is no impact at all. Generally we are moving in the right direction, but the government has no resources. Disabled people are aware and are in the forefront. It is the opportunities created that impact. Currently, disabled people have the right to send their children to a school of their choice. These are some of the inroads that have been achieved. In some cases, disabled have the right to employment in competitive corporate companies.
<b>Southern Africa (b)</b>		The situation in [state] has worsened. The politics, the fall of the dollar (hyper inflation) polarisation among political parties have put disabled people in a worse off situation than before. The closure of companies followed the failure of economic adjustment programmes (ESAPs) has had a negative impact on people of disabilities. There is now more begging, homelessness among disabled people than before. Even those that have been in homes are deserting the homes due to hunger.
<b>Eastern Africa (a)</b>	Yes	There is some positive change such as special schools being allocated funds by government to care for disabled children. Some companies and organizations are changing their perceptions of persons with disabilities and are now offering them jobs. Persons with disabilities access assistive devices at reduced costs due to the government zero rating tax on such items and a lot of awareness is being created and more parents of disabled children are seeking information on how to assist their children
<b>Eastern Africa (b)</b>	Too early	It is too early for me to assess.
<b>Eastern Africa (c)</b>		Follow up to the legislation and subsequent policies have resulted in increase of disability grants to DPOs, free

		appliances and assistive devices e.g. wheel chairs, white cane. Disabilities allowances, education grants and community support.
<b>Eastern Africa (d)</b>	No	There is nothing in the five years.

14. In order to ensure that disabled people had greater influence in the development of law or policy in your country, what do you think needs to be done?

<b>Respondent region</b>	<b>Response</b>
<b>Melanesia</b>	Disabled persons organizations be consulted for their input and then assured of involvement in all stages of the process.
<b>Southern Asia</b>	<ul style="list-style-type: none"> <li>• A strong Disability self-help movement need to come out.</li> <li>• Need to including PWDS issue as a development agenda mainstreaming to development process</li> <li>• Invest more money to build the capacity local level grass root organization and self help group</li> <li>• Establishment Disabled commission</li> <li>• Build the strong pressure group</li> <li>• Needed to equal participation and equal opportunity</li> <li>• International disability convention should be rectify and implement</li> <li>• International organization like DAA DPI must give pressure for the development agencies and international donor agencies to support the disability issue and movement</li> <li>• Support for health, education and employment</li> </ul>
<b>Southern Africa (a)</b>	Disabled people need to be mobilised into positions of influence in different organs. As we create these organs, we need to be vigilant. Empowering of disabled people is key. Lack of disability politics needs to be addressed as well.
<b>Southern Africa (b)</b>	I think their voice needs to be heard and respected. This is the most important thing that needs to be done. It needs to be recognised as well.
<b>Eastern Africa (a)</b>	Need to have organizations of persons with disabilities represented in the policy-making organs and any other decision making forum.
<b>Eastern Africa (b)</b>	<ul style="list-style-type: none"> <li>• There is need to build capacity of DPOs in relation to Policy issues</li> <li>• DPOs to be proactive, identify strategic issues for lobbying</li> <li>• Ensure that disability is mainstreamed in all existing policies.</li> </ul>
<b>Eastern Africa (c)</b>	Strong Disability movement with capacity to engage intellectually with the powers that be. There is no alternative to a strong movement that has the capacity.
<b>Eastern Africa (d)</b>	<ul style="list-style-type: none"> <li>• Government needs to have a political will</li> <li>• Support financially the federations of people living with disabilities</li> <li>• Individual DPOs are doing their own thing, they need to support the federation</li> <li>• Need for collaboration. This would foster a unity of purpose and speaking with one voice</li> </ul>

15. Are there any examples of disabled people having a positive influence on national legislation or policy in another country that you know of and would like to introduce in your own country?

<b>Respondent region</b>	<b>Yes/no</b>	<b>If 'yes', please provide a short description:</b>
<b>Melanesia</b>	No response	-
<b>Southern Asia</b>	Yes	-
<b>Southern Africa (a)</b>		<p>Good examples in Lesotho, Namibia, Swaziland that come to mind. Our major influence has been Scandinavian countries as well as the United Kingdom have worked with us.</p> <p>We continue to involve government and engage them at the intellectual level for disability programmes. We as well continue to create cadres of disabled people through exposure in research. We emphasize what we call intellectual property and the UK has been our example in this.</p>
<b>Southern Africa (b)</b>		<p>Yes. What is peculiar about [state] DPOs and activists is that we have trained many people that have gone to excel more. [State] is known world wide to be the citadel of DPOs creation ... Since then DPOs have been marching ahead, no going back and life has never been the same. Developments in other countries reveal that we should do what our students have achieved,</p>
<b>Eastern Africa (a)</b>	Yes	<p>A country like Uganda has embraced persons with disabilities, recognized their contribution in development and they now have disabled members in parliament who champion the rights of persons with disabilities, this is something we would also like our government to emulate.</p>
<b>Eastern Africa (b)</b>		<p>SAFOD gives me a great challenge. They introduced Equalization of Opportunities, Legislation Policy (EQUILAG). There are also organizations like NUDIPU, in Uganda. The President of that country, Yoweri Museveni introduced the best practice, very hospitable and positive policy for people with disability. If such could be emulated, we would be very far in our battles.</p>
<b>Eastern Africa (c)</b>	Yes	<p>The role that DPSA played in Southern Africa is a good example. Disability is part of the supreme law of that country (it is in the constitution of the country). And every policy and legislation derives its authority from the constitution. In other words citizenry in the country is guaranteed for disabled people.</p>

		Malawi and Uganda, there are Ministers responsible for disabled people's affairs. The fact that there is a disabled politician in Uganda shows that there is a willingness on the political front to include people with disability. Uganda is one of the best examples in Africa; it has over forty thousand political representatives from the village level.
<b>Eastern Africa (d)</b>	Yes	The Government of Namibia is very accommodative to people with disability in her country. It demonstrates best practices. They have elected to parliament a member of parliament who is disabled and is a woman. The government is sensitive and accommodative. They are moving in the right direction.

16. If you had the opportunity, what would you do differently to increase the influence of disabled people on national law or policy?

<b>Respondent region</b>	<b>Response</b>
<b>Melanesia</b>	<ul style="list-style-type: none"> <li>• Establish a Department of Disability under the Prime Ministers Office and recruit capable disabled persons in key positions within this Department.</li> <li>• This Department to develop right away a national disability policy and Act for endorsement by Government with clear enforcement and monitoring mechanisms.</li> <li>• Ensure that disabled persons organizations are involve in any disability-related programme or initiative.</li> </ul>
<b>Southern Asia</b>	Legal Aid and Legal advocacy program
<b>Southern Africa (a)</b>	<ul style="list-style-type: none"> <li>• To properly make sure that we properly employ cadres we deploy in strategic places.</li> <li>• We induct them properly.</li> <li>• To coach them and make sure they are properly mandated.</li> <li>• To network intensively.</li> </ul>
<b>Southern Africa (b)</b>	I will get them to demonstrate. Bring them in the street to demand their rights
<b>Eastern Africa (a)</b>	I would ensure different disabilities have representatives in all policy making organs as well as strengthening, lobbying and advocacy skills of all disability groups for them to push their agenda with one voice
<b>Eastern Africa (b)</b>	<ul style="list-style-type: none"> <li>• Want to see people with disability in key positions where they can influence legislation</li> <li>• Eastern Africa (b) Human Rights Committee should have an equal representation of people with disability in their board or structures</li> <li>• People with disability should e represented on such boards like the Eastern Africa (b) Law Commission and other institutions that fight for the disability cause</li> <li>• Want to see training on Policy Advocacy to disabled people.</li> </ul>
<b>Eastern Africa (c)</b>	I would make sure that there is some affirmative action and quarter system for disabled people to be represented at all levels from the village through to parliament. Responsibility passed to the office of the President and Cabinet.
<b>Eastern Africa (d)</b>	Given the opportunity to reorganize, I would conduct a national consultative workshop with DPOs. The purpose for this workshop is to come up with pertinent issues that would lead to a discussion of real issues for DPOs. The outcome would be our tool for going forward. I would meet with the line ministries for harnessing support. Then engage the government to adopt the document and make it a national issue worth a declaration. This approach would help harness support for the effective implementation of the cause.

	Only then, would I advocate for mechanism to be put in place for implementation.
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17. Can you provide examples of how laws or policies are really helping disabled people?

<b>Respondent region</b>	<b>Response</b>
<b>Melanesia</b>	None given
<b>Southern Asia</b>	<p>If we have clear policy and program it is really helping for the disabled people</p> <p>[State] had good policies and legislation for the PWDs even before the UN Standard Rule. In theory there is free education provision, in practice this is not so. I tried to get free education under the relevant legislation when I was at college.</p>
<b>Southern Africa (a)</b>	<p>On employment legislation, the government has dangled a carrot to companies that at least 2% of their staff complement should be people with disability. For the government itself, 2% of civil servants should be people with disability. This Act as already identified above is an incentive to companies, particularly to the private companies/sector, if they want to provide services to the government, the company should address issues of equity (i.e. addresses issues of disability). It is a fifty-fifty scenario. Government says if we support your company, or give it a business in procurement; demonstrate to us that you have implemented the above employment act. It helps to certain levels but the plain is still not even.</p>
<b>Southern Africa (b)</b>	<p>Laws are a fall back strategy. If you fail to achieve something that is protected by the law, is founded in law is a guarantee. It guarantees disabled people for their right. They do not have to beg. That is what I like about the law. It is a question of whether the disabled people know about that law. Where there are such laws, many disabled people do not know these laws. Most people live in rural areas and are not conversant with these laws.</p>
<b>Eastern Africa (a)</b>	<p>The disability legislation was passed but it is not being implemented so it not helping persons with disabilities</p>
<b>Eastern Africa (b)</b>	<p>A policy that has been introduced recently need to be given space. By way of conclusion, I would like to see DPOs in the region networking together so as to penetrate into the regional or continental institutions such as NEPAD and other continental initiatives.</p>
<b>Eastern Africa (c)</b>	<p>Laws or policies help in making rights of disabled people statutory and also they (disabled people) use these Laws or Policies to access community services in general systems of society. They also help in creating an enabling environment for disabled people in the society.</p>
<b>Eastern Africa (d)</b>	<p>I however have no example. These laws have never been case tested. Many women and children are abused. If reported, the case takes longer and financial resources become the strength of the</p>



	defendant. In other words people with disability are defeated at law not because the law is unjust, but because of the way the legislators leads their defence and the lack of financial resources by disabled people to engage good lawyers.
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### BIBLIOGRAPHY

- Ásgeirsdóttir, B. (2003), 'Opening Speech: Transforming Disability into Ability – Results and conclusions from the OECD's study of disability policies for the working-age population in 20 member countries', *Conference on 'Transforming Disability into Ability: Policies to promote work and income security for disabled people*, Vienna, 6-7 March 2003, OECD.
- Baquer, A. & Sharma, A, (1997), *Disability=Challenges v. Responses*, New Delhi: Concerned Action Now.
- Cutler, J. (2001) *Disability Legislation: A research report for DAA*, London: Disability Awareness in Action.
- Degener, T and Koster-Dreese, Y. (1995) *Human Rights and Disabled Persons*, Dordrecht: Martinus Nijhoff.
- Despouy, Leandro, (1990) *Human Rights and Disabled Persons*, New York: United Nations.
- Dube, A.K. (2005) *Participation of Disabled People in the PRSP/PEAP Process in Uganda, a research report for KaR Programme*, Norwich: UEA.
- Dube, A.K. (2005) *The Role and Effectiveness of Disability Legislation in South Africa, A report for KaR Programme*, Norwich: UEA.
- National Association for the Rights of Disabled People (April 2005) 'Disability Rights Annual Report on implementation of Law 220/2000, *Echoes of the Disabled*, Quarterly Magazine, Issue No. 51.
- European Day of Disabled Persons (1995) *Invisible Citizens, Disabled Person's status in the European Treaties*, Brussels: EDDP.
- Fleischer, D.J. and Zames, F. (2001) *The Disability Rights Movement, From Charity to Confrontation*, Philadelphia: Temple University Press.
- Fletcher, A. (1995) *Overcoming Obstacles to the Integration of Disabled People*, London: Disability Awareness in Action.
- Goggin, G. & Newell, C. (2005) *Disability in Australia, Exposing a Social Apartheid*, Sydney: University of New South Wales Press.
- International Disability Rights Monitor (2005), *IDRM Report on the Americas*, [www.cirnetwork.org/idrm/reports/americas/](http://www.cirnetwork.org/idrm/reports/americas/)
- International Disability Rights Compendium (2005), [www.cirnetwork.org/idrm-pdf/CIR\\_COMP.PDF](http://www.cirnetwork.org/idrm-pdf/CIR_COMP.PDF)
- Krieger, L.H. (2003), *Backlash Against the ADA, Reinterpreting Disability Rights*, USA: Michigan Press.
- Lansdown, G. (2002), *Disabled Children in South Africa, Progress in Implementing the Convention on the Rights of the Child*, London: DAA.

- Lansdown, G (2002), *Disabled Children in Romania, Progress in implementing the Convention on the Rights of the Child*, London: DAA.
- Lansdown, G (2003), *Disabled Children in Nepal, Progress in implementing the Convention on the Rights of the Child*, London, DAA.
- Lansdown, G (2003), *Disabled Children in El Salvador, Progress in implementing the Convention on the Rights of the Child*, London: DAA.
- Lansdown, G. (2003), *What Works*, London: Disability Awareness in Action
- Light R. J. (2002-2004), Successive reports on the UN Ad Hoc Committee, available at: <http://www.un-convention.info>
- Light, R. J. (2004) *Human Rights Data Summary Report*, London: Disability Awareness in Action.
- Light, R.J. (2000) *Civil Rights and Disabled People*, Resource Kit 7, London: Disability Awareness in Action.
- Oddy, C. & Davison, B. (1996) 'Disabilities in the European Union, the Need for a non-Discrimination Clause in the Treaty of Rome', 3, Cophall House. Station Square, Coventry.
- Oliver M. (1981) 'A New Model of the Social Work Role in Relation to Disability' in Jo Campling (ed.) (1981) *The Handicapped Person: a New Perspective for Social Workers?* London: RADAR;
- Oliver, M. (1983) *Social Work With Disabled People*, London: Macmillan.
- Oliver M. (1990a), *The Politics of Disablement*, Tavistock: Macmillan.
- Oliver, M. (1990b), 'The Individual and Social Models of Disability', Research Paper presented at the *Joint Workshop on the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities In Hospitals*, 23 July 1990, <http://www.leeds.ac.uk/disability-studies/archiveuk/Oliver/Oliver.htm>
- Oliver, M. (1992), 'Changing the Social Relations of Research Production?', *Disability, Handicap and Society*, Vol.7, No.2, pp. 101 - 113.
- Oliver, M. (1994), *Capitalism, Disability and Ideology: A Materialist Critique of the Normalization Principle*, <http://www.leeds.ac.uk/disability-studies/archiveuk/Oliver/Oliver.htm>
- Oliver, M. (1996), *Understanding Disability: From Theory to Practice*, Basingstoke: Macmillan Press.
- Oliver, M. and Barnes, C. (1994), 'Discrimination, disability and welfare: from needs to rights' in Swain, J.; Finkelstein, V.; French, S. and Oliver, M. (eds) (1994), *Disabling Barriers - Enabling Environments*, London: Sage Publications in association with the Open University.
- Oliver, M. and Barnes, C. (1998) *Disabled People and Social Policy: From Exclusion to Inclusion*, London: Longman.
- Oliver, M. and Sapey, B. (1999), *Social Work with Disabled People*, Basingstoke: Macmillan Press.

- Petersmann, E.-U. (2001), 'Time For Integrating Human Rights into the Law of Worldwide Organizations: Lessons from European Integration Law for Global Integration Law', *Jean Monnet Working Paper 7/01*, New York: New York University School of Law.
- Rehabilitaton International & UN CSDHA, (1986) *Report of the International Expert Meeting on Legislation for Equalisation of Opportunities for People with Disabilities*, Vienna: Austrian Workers Compensation Board.
- Stapleton, D. C., Burkhauser R. V., & Houtenville A. J. (2004) *Has the Employment Rate of People with Disabilities Declined?*, *Policy Brief, Employment and Disability*, Washington DC: Rehabilitation Research and Training Center for Economic Research on Employment Policy for Persons with Disabilities.
- Stone, E. (ed.) (1999), *Disability and Development: Learning from Action and Research on Disability in the Majority World*, Leeds: Disability Press.
- Thornton, P. and Lunt, B. (1995), *Employment for Disabled People: Social Obligation or Individual Responsibility?*, York: SPRU.
- Townsend, P. and Donkor, K. (1996), *Global Restructuring and Social Policy: The need to establish an international welfare state*, Bristol: Policy Press.
- Tucker, B.P. (2001) 'The ADA's Revolving Door: Inherent Flaws in the Civil Rights Paradigm', 62 *Ohio St. L.J.* 335.
- Walker, B. ed (1995) *Disability Rights, A report of a Symposium of the European Regions*, Hampshire: Hampshire Coalition of Disabled People.
- Wilding, P. (1997), 'Globalization, regionalism and social policy', *Social Policy and Administration*, 31, 4: 410-28.
- Yeates, N. (1999), 'Social Politics and Policy in an Era of Globalization: Critical Reflections', *Social Policy & Administration*, Vol. 33, No. 4, December 1999, pp. 372-393.