Disability KaR
Knowledge and Research

Executive Summary

Promoting inclusion?

Disabled people, legislation and public policy

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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.[1]

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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[1] 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

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.