1. Executive Summary

1.1 This submission addresses governance issues within disability policy-making and programming in developing countries. It is not possible to effectively implement progressive, rights-based policies and programmes without taking the broader contextual governance issues into account.

1.2 In particular the submission considers:

- the political, social and economic context in which disability policy-making and programming occurs; and
- the role that disabled people’s organisations play in the international development arena.

1.3 Disabled people’s organisations are run and managed by disabled people themselves. Their primary function is to promote and enforce disability rights both within their own countries and internationally. Potentially, they have a vital strategic role to play in holding their governments to account in relation to their disability rights commitments, as well as providing an invaluable resource to bilateral and multilateral donor agencies in planning and implementing genuinely inclusive disability initiatives. However, there is a need to take a realistic assessment regarding the organisational and institutional capacity of disabled people’s organisations to play such a role.

1.4 From previous research undertaken by the Leonard Cheshire Disability and Inclusive Development Centre, it is apparent that there are some significant and common barriers to the effective implementation of disability policy and programming, some of which can be attributed to broader government frameworks often found in developing countries. These can include:

- limited understanding of a human rights-based approach as these relate to disability issues in social and economic policy-making;
- a lack of appreciation of the rule of law, accountability and transparency;
- a disjuncture between policy making and implementation; and
- the lack of capacity of some national statistical offices to understand disability issues, which adversely affects their ability to generate meaningful disability statistics, and results in difficulties in planning and implementing effective and efficient disability policy.
1.5 Furthermore, in the absence of robust statistical data, a “democratic deficit”\(^1\) can be created whereby civil society institutions, including disabled people’s organisations, often do not have the indices and base-data evidence to hold their respective governments to account in relation to disability rights commitments.

1.6 Disabled people’s organisations have a vital role to play in international development. However, there are some significant issues that need to be addressed if they are to play an effective role in advocating and upholding disability rights in their respective countries. In many developing countries, disabled people’s organisations can lack the institutional and organisational capacity to carry out this function effectively. Other issues that can impact on disabled people’s organisations include their often being based in capital cities, with insufficient outreach to rural areas; or that their leadership may be dominated by “elites” (disabled individuals from middle- and upper-class background whose concerns and political agendas may not be the same as the poorer disabled members of their communities). In many countries there are also single-impairment disabled people’s organisations (relating to a specific impairment, for example, hearing loss) but often few or no pan-impairment organisations. This can lead to competition between organisations, both in terms of claiming legitimacy (who is entitled to speak on behalf of the ‘disability community’) and for finite financial resources.

1.7 Issues of capacity can also often impact on organisations, where smaller disabled people’s organisations may simply not have access to a wide-range of transferable skills (such as strategic planning, budgeting, accounting and personnel management) that are necessary for their long-term sustainability and effectiveness.

1.8 It is recommended that funding be provided to disabled people’s organisations specifically to enhance their organisational capacity and to strengthen any deficit in transferable skills.

2. The Leonard Cheshire Disability and Inclusive Development Centre, University College London

2.1 The Leonard Cheshire Disability and Inclusive Development Centre, University College London (which is part of Leonard Cheshire Disability’s International Department), undertakes world-class qualitative and quantitative research in the field of disability and international development. We focus on policy analysis, disability and poverty, livelihoods, inclusive education and disability in conflict-affected countries and in disaster and emergency situations\(^2\). The Centre has undertaken a portfolio of policy focused research regarding disability and international development. These include Disability Scoping Studies funded by DFID in Zimbabwe (2007)\(^3\), Nigeria (2008)\(^4\), and Uganda (2009)\(^5\). In addition, in

---


\(^2\) [www.ucl.ac.uk/lc-ccd](http://www.ucl.ac.uk/lc-ccd)

In collaboration with the Southern African Federation of the Disabled, the Centre has undertaken a Disability Policy Audit in Namibia, Swaziland, Malawi and Mozambique\(^6\). Most recently, the Centre managed a three year DFID-funded Crosscutting Disability Research Programme\(^7\), which had a strong policy focus. The main objective of this programme was to incorporate a disability component into other DFID-funded research programmes. This was achieved in five countries, (Kenya, Uganda, Zambia, Nepal and India), encompassing the fields of maternal and child health, urban agriculture, mental health, and water and sanitation issues. There will also a strong capacity building element to this programme, including the development of a toolkit to assist disabled people’s organisations in using primary and secondary research findings in their core campaigning and advocacy activities\(^8\).

3. **Evidence submission**

**Disability, International Development and Governance**

3.1 From previous policy-focused research undertaken by the Leonard Cheshire Disability and Inclusive Development Centre, it is apparent that there are some common trends related to governance issues that can impact on the effective implementation of disability policy and practice in developing countries\(^9\). These issues have a significant negative impact upon the extent to which human rights-based policy and practice can be implemented, both by national governments and by bilateral and multilateral donor agencies. These common barriers to implement effective disability policies and programmes include the following:

3.2 The institutional architecture of governance frameworks in some developing countries can be characterised by:
- a lack of understanding of the principles of the rule of law;
- a lack of transparency and accountability;
- the necessity for addressing disability policy as a cross-cutting issue;
- the disjuncture between policy formulation and implementation; and
- the lack of an efficient and effective administrative infrastructure for service provision for disabled people.

3.3 Public appointments at national, regional and local levels are often made on the basis of patronage.

---

\(^4\) Lang, R., Upah, L. (2008), Disability Scoping Study in Nigeria. London: DFID.
\(^5\) [http://www.ucl.ac.uk/lc-ccr/downloads/06052009_Disability_Scoping_Study_Uganda.pdf](http://www.ucl.ac.uk/lc-ccr/downloads/06052009_Disability_Scoping_Study_Uganda.pdf)
\(^7\) [http://www.ucl.ac.uk/lc-ccr/ccdrp](http://www.ucl.ac.uk/lc-ccr/ccdrp)
\(^8\) [http://www.ucl.ac.uk/lc-ccr/ccdrp/downloads/DPO_toolkit.pdf](http://www.ucl.ac.uk/lc-ccr/ccdrp/downloads/DPO_toolkit.pdf)
3.4 Policy-makers perceive disability as a specialist and expensive policy area to address, and it is therefore considered a low priority in relation to other competing development challenges.

3.5 The formulation of social and economic policy in every sphere, including disability issues, is premised on the ideological foundations of charity and welfare, rather than human rights.

3.6 National statistical offices in many developing countries often do not have the capacity and knowledge of disability issues to generate meaningful and robust disability statistics. Therefore there is a paucity of robust statistical data regarding the prevalence and nature of impairments, which hampers the effective delivery of disability services. This results is the creation of a "democratic deficit"\(^1\), as government and civil society institutions lack enough data to evaluate what progress has been made regarding disability rights and the extent to which disabled people are actively participating in the society in which they live.

The Role of Disabled People's Organisations

3.7 In most developing countries, disabled people’s organisations exist, whose mandate is to promote and ensure that disability rights are upheld. Potentially, they have a crucial and vital role to play in their respective countries, particularly in relation to holding their respective governments to account. Some disabled people’s organisations are very effective. However, other organisations can lack the necessary organisational capacity to be effective in undertaking this function. It is imperative that a realistic assessment is taken regarding the role that such organisations play within international development, both in terms of influencing and setting the agenda for domestic policy and programming, as well as interacting with bilateral and multilateral donor agencies.

3.8 With notable exceptions, it has been found that disabled people’s organisations and policy-makers often do not understand each other’s worldview. Too often the former have limited experience of the intricacies of the policy-making process, while the latter frequently do not understand disability issues from a human rights perspective. This can result in a situation where there is little common ground, and opportunities for meaningful collaboration can be lost.

3.9 There are also sometimes questions surrounding the democratic credentials of some disabled people's organisations, which can be populated by the "elites" within the disability movement, with women and young people being significantly under-represented within their governing structures.

3.10 Issues of capacity can also impact on disabled people’s organisations, as some organisations simply do not have access to broader transferable skills (such as strategic planning, budgeting, accounting and personnel management) necessary

for long-term sustainability and effectiveness. The result of this lack of skills can be significant. For example, there are instances where such organisations have been funded by bilateral and multilateral donor agencies to undertake specific programmes, but capacity issues and a lack of critical financial or administrative skills has led to organisations being unable to deliver agreed outcomes. As a consequence, applications for additional funding from such donors have been unsuccessful – even when such disabled peoples’ organisations have had significant accomplishments to show.

3.11 It is recommended that funding be provided to disabled people’s organisations specifically to enhance their organisational capacity and to strengthen any apparent deficit in transferable skills.

3.12 In many developing countries, disabled people’s organisations are based in capital cities, and despite concerted efforts, do not have the capacity to effectively reach out to disabled people living in rural areas. In such cases the views of the majority of disabled people, who according to the WHO continue to live in rural environments, are often not represented in the policy-making processes and programming decisions.

3.13 In some countries, such as India, there is not one single pan-impairment disabled people’s organisation that can credibly claim to represent the views of all disabled people in their country. Rather, there are a plethora of single impairment disabled people’s organisations (for example, for those with visual and hearing impairments, and those with spinal cord injuries). This results in a lack of unified voice within the disability community. Such a scenario often also results in competition between disabled people’s organisations, both for legitimacy and for finite human resources.