Disability: still excluded from development agenda?

Messages from the Disability Knowledge and Research (KaR) Programme

Disability KaR Knowledge and Research

ODG DEV

DFID Department for International Development

Disability KaR
Knowledge and Research

- **The Disability Knowledge and Research Programme (Disability KaR) has been…**
- …one of the most ambitious, wide-ranging and innovative research projects on disability and development ever carried out
- …led and managed by disabled people from the South and North.

Disability KaR

- The Disability Knowledge and Research (KaR 2) programme ran from September 2003 to September 2005, following the completion of KaR 1 (2000-2003). While the first phase had incorporated a healthcare technology (HCT) focus, and elements of this were retained through existing commissioned projects, KaR 2 concentrated more directly on the issue of disability and poverty, particularly looking at mainstreaming disability in development.

From medical to social model

- The social model of disability formed the basis of the programme, in terms of a conceptual approach to understanding disability and as a result of growing involvement of disabled people in the programme.
- "Nothing about us, without us"
- "Professionals on tap not on top"

Involving Disabled People

- initiated a consultation amongst Disabled People's Organisations (DPOs), north and south, about areas of research need, and following this a research prospectus was drawn up reflecting the needs as defined by DPOs and their representatives.
- The tendering process identified predominantly disabled researchers, many based in the south, to carry out the research.
- Disabled researchers also became involved in the programme's *Policy Project* research, and *Enabling Disabled People to Reduce Poverty* project.
- Other activities within the programme facilitated this process, particularly the three roundtables held in India, Malawi and Cambodia.

Changing the social relations of research

- The effect of involving disabled people (predominantly from the south) in this way has been to challenge the traditional methods in which disability and development research is carried out.

- It has ensured that disabled people have been active participants in a process / programme that seeks to address issues pertinent to them, but about which they previously had little say.

- It is arguable that this is the most significant overall achievement of the programme.

KaR and DFID

- Another key aspect of the programme was the appointment, and location within DFID, of the programme's Disability Policy Officer

- In addition to providing technical advice on disability to DFID, the Policy Officer initiated a series of research activities exploring DFID's support of disability projects and incorporation of a disability focus to its international development work

- By the end of her assignment, the profile of disability had risen considerably within DFID and is now explicitly addressed by the newly formed Exclusion, Rights and Justice (ERJ) team

- The Policy Project has had a far reaching effect in terms of internal organisational education about critical disability issues for DFID, and drawing attention to the challenges faced.

Training Course
'Mainstreaming Disability in Development' (May 2005)

- 15 participants from 8 countries participated, with mainstreaming explored at 4 levels: country programming (including DFID CAPs and national PRSPs); development interventions (including a variety of aid instruments); institutionally within organisations; and knowledge initiatives (looking at disability and research).
- Using participatory methods and sharing case-studies and presentations the course identified practical ways of including and involving disabled people in the development process.
- Participants devised an action plan to take back to their organisations.

Thematic Research

Two levels of consultation:

1. Initial consultation by the Policy Officer with members of the disability movement in Europe, Africa and Asia.

2. Consultation at the programme's first 'roundtable' in Malawi (November 2004). Roundtable participants identified research areas, from which 7 were agreed, and also drew up a list of guiding principles for research and policy development.

Guiding Principles

- Include democratic and accountable voices of disabled people
- Reflect diversity of disabled people
- Resource voices of disabled people
- Facilitate equality of power relationships
- Conduct emancipatory research/policy development – be empowering
- Have active and equal partners
- Professionals should be 'on tap' not 'on top'
- Disabled people should be seen as experts in own lives/situation
- Have equal value of expertise – recognise power relations within expertise
- Benefit disabled people
- Include knowledgeable and skilled disabled people relevant to the topic
- Be inclusive of all disabilities within the range of research topics
- Be gender sensitive

Areas of priority for research

- GAP Analysis
- Policy and Legislation
- Data and Statistics
- Mainstreaming Disability
- Are Disabled People's Voices from South and North being heard in the Development Process?
- Conflict and Emergency Situations
- Education

Disability KaR – final report

" Whilst the overall purpose is to improve health and quality of life for poor people generally, the programme has concentrated on a marginalised section of the poor - disabled people. Disability is a cross cutting issue in terms of poverty and the reasons why people become and stay poor, and the programme demonstrates that if marginalised people themselves are entrusted with defining and identifying solutions to the issues pertinent to them, the resulting activities will incorporate a stronger focus and reflect development needs much more sharply".

Developing participatory rural appraisal approaches with disabled people in Cambodia

- This research was undertaken by a local NGO – Disability Development Services, Pursat (DDSP) in Pursat Province, Cambodia. The goal of the research was to examine rural disabled people's role in all stages of a participatory rural appraisal (PRA)

- The aims being to maximise control of the research process by rural disabled people, and increase participation of disabled people in village PRA activities.

- The majority of team members were inexperienced, uneducated rural people with severe disabilities, including learning disabilities, and training in PRA techniques was given.

- The disabled team members demonstrated skills in problem identification, identifying income-generating activities, household-wealth surveying and drawing time lines for disabled people's daily activities.

- Results were fed into DDSP's action plan, and as a result of the research, community level awareness about disability was raised. Most crucially, the capacity of disabled people to be involved in community development analysis was increased, and the traditional power relations between NGO and clients were challenged. See the following web-link for the full report. http://www.disabilitykar.net/research/small_pra.html

Participation of disabled people in the Poverty Reduction Strategy Plan (PRSP) & Poverty Eradication Action Plan (PEAP) process in Uganda

- This research documented the experience of the disability movement in Uganda, the National Union of Disabled People in Uganda (NUDIPU) with the development of Uganda's PEAP.
- It found that involvement in the PEAP was significant as a result of NUDIPU lobbying to be involved, and a willingness of the government to include them.
- NUDIPU also encouraged consultation with NGOs at district and sub-county levels, and formed alliances with the NGO Forum and government departments and ministries.
- Whilst inputs were made into the PEAP process the time for consultation was very short and DPOs at a local level felt they did not have the capacity to respond to calls for input as quickly as required.
- DPOs also felt that if governments and donors are committed to getting contributions to the PEAP, they need to offer financial support to enable organisations to respond
- Web link: www.disabilitykar.net/research/

Capacity Building of Disabled People's Organisations in Mozambique

- This research examined the role and efficacy of capacity building initiatives, by northern NGOs and DPOs, of DPOs and NGOs in Mozambique.
- It found that Mozambican NGOs are clear that, for them, capacity building is about 'creating legs with which to walk'.
- This means not only technical input and support but financial support to enable them to continue what they have learnt.
- However northern NGOs have a more limited understanding which focused on technical input only, often using the skills of northern experts, and leaving local NGOs/DPOs feel disempowered, rather than empowered.
- Partnerships work well where there is a shared understanding of the philosophy of the disability movement between southern and northern organisations.
- See: http://www.disabilitykar.net/research/small_moz.html

Promoting Inclusion? Disabled People, Legislation and Public Policy

- Aim: Critical analysis of the impact on, and value of, disability legislation/policy on lives of disabled people, including disabled peoples' influence on the legislation process.
- Findings:
- Legislation should operate in a human rights dimension;
- The Social model of disability needs to be embedded within legislation and policy if it is to be effective;
- Legislation must be mandatory, adequately funded and enforced;
- Legislation and policy must be driven by evidence concerning the reality of 'disabled lives';
- Disabled people's contribution to legislation and policy needs to be increased and valued;
- Partnerships that are formalised and resourced between DPO and governmental actors make for effective legislation and policy agendas.
- http://www.disabilitykar.net/research/thematic_legis.html

Data and Statistics on disability in developing countries

- Aim: Analysis of data and statistics in developing countries.

Findings:

- Disability statistics in low-income countries is mainly made up of impairment based figures which the research argues provides a limited picture of the way in which disability affects people's lives.

- More valuable data would comprise measuring activity limitation, and/or restrictions in social participation, amongst all regardless of the presence of any impairment.

- http://www.disabilitykar.net/research/thematic_stats.html

Are Disabled People's Voices from South and North being heard in the Development Process?

Aim: To identify to what extent disabled people and DPOs are involved in strategies, policies and funding for addressing the poverty of disabled people.

Findings:

- Disabled people and DPOs are marginalised in terms of having voice in development programmes affecting them.
- Donors need to target DPOs directly for support in development programmes, and conditions attached to funding need to be removed.
- DPOs require resources to build capacity, particularly so that they can conduct advocacy activities at government level.

http://www.disabilitykar.net/research/thematic_voices.html

Disability and Conflict in Emergency Situations: focus on Tsunami-affected areas

- Aim: Assess the extent of inclusion of disability in emergency, conflict and refugee programmes, including the impact of networking and role of resources in post-tsunami contexts

Findings:
- DPOs had little involvement in post-tsunami reconstruction efforts, with European aid workers speaking on their behalf.
- Whilst the concepts of inclusion and the social model of disability were understood but there was an inability to understand how this could be translated into practise.
- Consultation also gave way to a pressure to spend money quickly.
- The combination of these factors meant that there was little evidence that DPOs and poor disabled people were recipients of aid in any form

http://www.disabilitykar.net/research/thematic_conflict.html

Five key messages that emerge from the research

- Disability is not about health status, it is about discrimination and systematic exclusion. It must be seen and addressed as a question of fundamental human rights;

- Meaningful research to support sustainable development demands that disabled people and DPOs take a leading role and not simply be 'included' or 'consulted';

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- DPOs need support which builds and sustains their capacity and not the capacity of International NGOs that all too often act as intermediaries;

- Governments and development agencies need to tackle the problem of policy evaporation which has meant that good policies on mainstreaming disability in development remain trapped on paper;

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Development agencies/donors themselves must set an example on inclusion and equality by:

- employing more disabled people

- drawing on the experience and expertise of DPOs both in the North and South

- giving direct support to DPOs in South and North

Equalise It!

A Manifesto for Disability Equality

Website

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