



Messages from Research

Disability Knowledge and Research (KaR) Programme

Funded by

DFID Department for
International
Development

Bill Albert & Mark Harrison

The Disability Knowledge and Research Programme (Disability KaR) (2003-05), funded by the UK's Department for International Development (DFID), had a number of different major elements.

<http://www.disabilitykar.net/>

Besides an extensive research agenda – the main focus of this booklet – it also included ongoing disability policy advice to DFID, three Southern-based roundtables, newsletters, six technical projects, training workshops and a dedicated website. For a detailed overview of the research programme see the final learning publication:

<http://www.disabilitykar.net/learningpublication/contents.html>

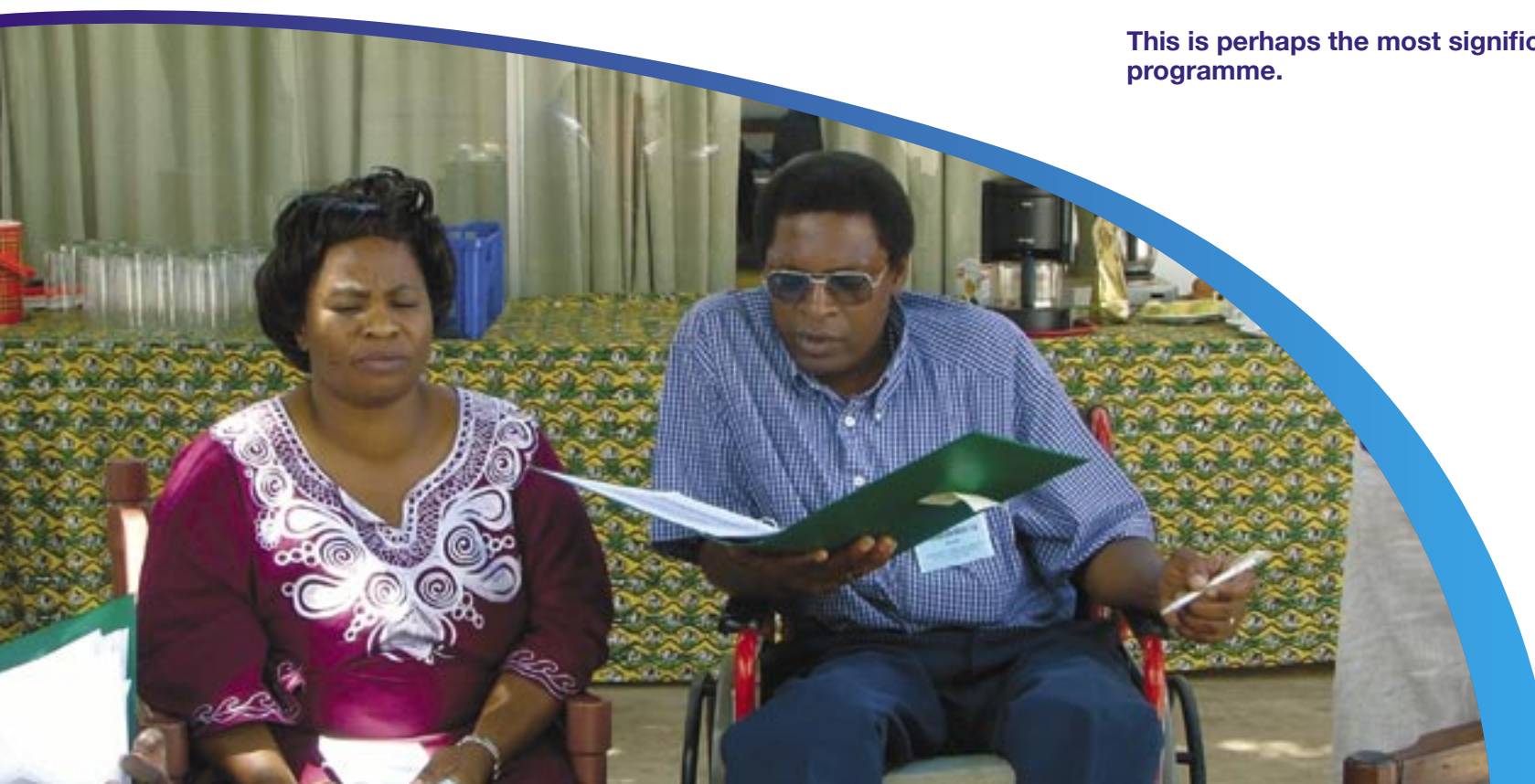
The Disability Knowledge and Research Programme (Disability KaR) has been...

- ... 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.

Because of this the Disability KaR has...

- ... ensured that disabled people have been active participants at all stages in the research process
- ... challenged the traditional top-down way in which disability and development research is carried out.
- ... provided a model of emancipatory research grounded in the experience and expertise of disabled people

This is perhaps the most significant overall achievement of the programme.



Disability KaR
Knowledge and Research

DEV
ODG

UEA
NORWICH

healthlink
WORLDWIDE
www.healthlink.org.uk

Ideas/Ideals that have underpinned the KaR Programme

Disability and human rights

'Disability is a human rights issue! I repeat: disability is a human rights issue.'

Bengt Lindqvist, UN Special Rapporteur on Disability

"International Development Targets can only be achieved with the engagement of poor people in the decisions and processes which affect their lives. Human rights are a central part of work to achieve the International Development Targets because they provide a means of empowering all people to make effective decisions about their own lives."

UK Department for International Development

'NUDIPU perceives the cause of PWDs (people with disabilities) as a human rights issue and aims at liberation and empowerment. The focus of empowerment and liberation is on developing potentials, raising awareness and removal of barriers to integration in society and enjoyment of human rights. Disability is a human rights issue.'

National Union of Disabled People of Uganda

Disability and self-representation

"States should recognise the rights of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognise the advisory role of organisations of persons with disabilities in decision making on disability matters"

States should encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and or advocates. States should recognize that those organizations have a role to play in the development of disability policy.

From Rule 18 of the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities



Disability and development

'Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the chance to achieve a primary education by the same date – goals agreed to by more than 180 world leaders at the UN Millennium Summit in September 2000'

James Wolfensohn, former President of the World Bank

'A rights based approach to disability and development is about levelling the playing field so that people with disabilities can access jobs, education, health and other services. A rights based approach is about the removal of physical and social barriers; it is about attitude adjustments for policy makers, employers, teachers, health care professionals and even family members.'

SAFOD (Southern African Federation of the Disabled)

"Realising key International Development Targets, such as universal primary education, would be impossible without including disabled people. If the interests of disabled people are not recognised then the key goal of poverty reduction in developing countries will not be achieved. Nor will the human rights of people with disabilities or their participation in society be promoted."

EU Guidance Note on Disability and Development (2003)



Deciding what to Research

The Disability KaR's three research strands

Research on enabling disabled people in poverty reduction

Research topics decided by...

... formal appraisal by disabled researchers of first Disability KaR programme

Research carried out by...

... disabled people and...

... overseen by Project Advisory Group (PAG) with disabled people from both the North and South in a majority

Policy Project research

Research topics decided by...

... KaR Policy Officer working closely with...

... UK disability movement and PAG

Research carried out by...

... KaR Policy Officer and...

... disabled researchers commissioned on small scale projects

Commissioned thematic research

Research topics decided by...

...consulting with members of the disability movement in Europe, Africa and Asia, as well as...

consultation with DPOs at the programme's first roundtable in Malawi

Research carried out by...

...collaborative projects involving disabled researchers from the South and North

Research on enabling disabled people in poverty reduction

Mainstreaming disability in development: lessons from gender mainstreaming

Key Messages

There are important lessons for DFID and other agencies to learn from the experience of trying to mainstream gender in development

These include the need for:

- a clear policy mandate and implementation strategy on disability
- robust institutional structures to promote a disability equality agenda
- an organisational culture that is supportive of disability equality and staff that have the skills needed to mainstream disability
- policy relevant research and information
- practical guidelines and tools to mainstream disability
- the involvement of disabled people and disabled people's organisations both North and South at all levels
- building disability issues in at the start of projects
- new strategies to ensure mainstreaming within new aid instruments
- appropriate tools for monitoring progress and outcomes

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

The social model of disability, human rights and development & Disability and a human rights approach to development.

Key Messages

These two linked briefing papers argue that:

- The social model of disability (that people are disabled by society not biology) represents a protean challenge to traditional medical-influenced thinking about disability.

- The social model of disability makes the most sense in terms of an emancipating, participatory, human rights approach to development.
- Putting this approach into practice means addressing disability - institutionalised discrimination and inequality.
- Sustainable change can only happen when disabled people and their organisations are actively involved in identifying their needs.
- A human rights approach to development can only succeed if user led civil society organisations, including DPOs, are afforded capacity-building support so they can take part on equal terms, consult and inform their members and hold their governments to account.

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

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

Disability, poverty and the new development agenda

Key Messages

This report offers a radical critique of poverty and disability, arguing that:

- The relationship between disability and poverty has often been referred to as a vicious circle, but this obscures the similarities between the processes of marginalisation experienced by disabled people and poor people.
- The assumption that inclusion is desirable, for example, in IMF/World Bank poverty reduction programmes, fails to take into account arguments that it is these programmes and the globalisation agenda which they support that help create and perpetuate intractable poverty.
- A more critical assessment of the impact of neo-liberal political economy on poor people is urgently required and alliances need to be built between marginalised groups if there is to be any real chance of creating a more humane and just society.

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



Policy Project Research

The Disability KaR Project Office

The appointment, and location within DFID, of the programme's Disability Policy Officer was of key importance in that...

... in addition to providing technical advice on disability to DFID she initiated a series of research activities exploring the Department's support of disability projects and issues around mainstreaming and...

... it had a far reaching impact in terms of internal organisational education about critical disability issues for DFID and drew attention to the challenges faced and...

... by the end of the policy project the profile of disability had risen considerably within DFID and is now explicitly addressed by the newly formed Exclusion, Rights and Justice (ERJ) team

DFID and Disability: A mapping of the Department for international development and disability issues

Key Messages

This detailed report, carried out by the Policy Officer at the start of the Disability KaR programme, catalogued what DFID was doing on disability and found that:

- There is a considerable range of disability specific activities being funded by DFID and largely carried out by NGOs and civil society organisations (CSOs)
- DFID's work on disability is largely hidden, with staff and country offices frequently unaware of disability focused activities being done by organisations supported by the Department
- Although staff broadly recognise the links between poverty and disability, they do not necessarily see disability as an essential part of their work on poverty reduction and the achievement of the Millennium Development Goals (MDGs)
- "... there is little practical evidence that mainstreaming has taken place and disability has hardly registered at all in the development process"
- DFID staff need more information on disability, in particular practical tools and examples of best practice, to enable them to implement the twin track approach outlined in DFID's 2000 Issues Paper 'Disability, Poverty & Development'

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

Disability, poverty and the Millennium Development Goals: relevance, challenges and opportunities for DFID

Key Messages

The Policy Officer's final report concluded that...

- despite progress, disability is still not seen a key component of DFID's corporate goal of poverty reduction
- the new aid instruments continue to prevent DFID supporting and influencing the CSOs most likely to be working on disability issues
- technical support on disability within DFID will need to be addressed once the Disability KaR is wound up
- There is a need to:
 - articulate a clear position on disability and develop an implementation strategy;
 - recruit more disabled staff at DFID;
 - Include disability in poverty analysis and data collection;
 - support DPOs;
 - continue to support disability research

"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".

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

Developing participatory rural appraisal approaches with disabled people in Cambodia

Key Messages

... the highest disability prevalence rate appeared to be in the least isolated village with the best social and economic opportunities, which raised questions about the links between poverty and disability

... quantitative data on relative wealth of households with and without a disabled person was equivocal, although it appeared that households with a disabled woman have fewer livelihood assets than households with a disabled man

... disabled people are able to rise to high positions of authority in the community, and

other community leaders have disabled family members which may influence their opinion on disability issues

The research process with disabled people involved at all levels led to ...

- ... a realisation of the untapped skills of disabled researchers, and...
- ... a more positive perception of disabled people by the community and...
- ... the increased capacity of disabled people to be involved in community development analysis, and ...
- ... a strong challenge to the traditional power relations between NGO and clients.

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

Key Messages

- DPO involvement in the PEAP was significant but only as a result of strong lobbying by NUDIPU
- inputs were made into the PEAP, but the time for consultation was very short, DPOs at a local level felt they did not have the capacity to respond to calls for input as quickly as required and there was a feeling that in the end they were squeezed out of the process
- DPOs also felt that if governments and donors are committed to getting their contributions to the PEAP, they need to offer sufficient time and financial support to enable organisations to respond
- Some felt that the government was using DPO involvement as a way of legitimizing the PRSP process, rather than out of genuine interest in the rights and needs of disabled people
- To ensure PRSP promises were delivered, cross-cutting disability indicators and performance benchmarks have to be developed and put in place

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

The role and effectiveness of disability legislation in South Africa

Key Messages

- Support for the formulation and adoption of a wide range of disability policies has been excellent, but its implementation remains a challenge. This has been due to:
- Capacity constraints at programmatic level that limit the effective implementation of policy.
- Policy implementation issues not being addressed consistently at different levels of government because of limited conceptual understanding, poor championing, inadequate or inappropriate institutional arrangements, and a general lack of capacity.

Also...

- ... the definition and nature of disabled people's participation has not been adequately reviewed and articulated, and...
- ... the policy requirements for disability mainstreaming are not adequately linked to performance management, thereby undermining commitment to implementation, and..
- ... legislation and policies are not implemented due to a lack of allocated fiscal resources and commitment, and...
- ... where successful implementation has occurred, it has largely been due to political support by the Minister and senior civil servants in charge of departments and/or the sustained commitment and ongoing advocacy by the disability sector led by Disabled People South Africa (DPSA).

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



Capacity Building of Disabled People's Organisations in Mozambique

Key Messages

- Mozambican DPOs are clear that capacity building is understood by them as giving them “legs with which to walk, or on which to stand”..
- DPOs think that the approach of some Northern NGOs to capacity building is limited, seeing it only in terms of training
- DPOs see the need for complementary support to cover of core costs so enabling them to implement what has been learned
- DPOs are concerned about over-reliance on foreign experts instead of using local capacity.
- DPOs are angry at what they see as unequal power relations, with their Northern NGO partners, raising money from the North in the name of disability but not discussing more openly and flexibly how the money should be spent.
- Through this process DPOs are not really being empowered to stand independently or to approach donors in their own right
- The Northern DPOs are particularly appreciated for their empowering attitude which treats their Southern counterparts as equals, who they respect and listen to. The shared values of the disability movement contribute to this more equal relationship.

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

Commissioned thematic research

Guiding principles for thematic research established at the Disability KaR Roundtable in Malawi

- 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

http://www.disabilitykar.net/roundtables/malawi_rt.html



The nine topics for thematic research were drawn from ideas put forward at a meeting of representatives of Southern and Northern DPOs and from the following list set out at the Disability KaR Roundtable in Malawi

Areas of priority for disability research

- Poverty and disability
- Legislation and poverty
- Development aid and DPOs
- Data collection
- Prevention of disability
- Education
- Humanitarian situations and conflict
- HIV/AIDS
- DPOs
- Transport

The thematic research was carried out between January and June 2005. Seven research topics were commissioned following an inclusive tendering process during in which 27 applications were received, with proposals covering the nine themes put forward in the research prospectus.

Proposals were graded according to a six point selection criteria, and all but one of the research managers were disabled people, supported by a team of disabled and non-disabled people from the North and South. DPOs played a significant part in managing the majority of the projects and represented a significant group involved in the research process.

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



Gaps in research on disability and development

Key Messages

DPOs and development agencies saw the following as major areas for research.

- Researching emancipatory research
- Education
- Poverty and disability
- Disasters and post-conflict situations
- Disability and new aid Instruments
- Development aid and strengthening DPOs
- HIV and AIDS
- Legislation and policy

The report also highlighted demands from DPOs for a lead role in the research process. It was argued that:

- The most productive way forward research is to adopt an emancipatory approach that puts disabled people in the forefront but also embraces genuine partnership working with academics or other professionals. And that...
- By ensuring that disabled people are moved upstream in the process this would be consistent with both the demands from Northern and Southern DPOs and bring into play DFID's own commitment of "... enabling people to realise their rights to participate in, and access information relating to, the decision-making processes which affect their lives."

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

Promoting inclusion? disabled people, legislation and public policy

Key Messages

- Legislation is invariably inadequately funded and/or subject to ineffective monitoring and enforcement.
- Enforcement mechanisms that exist place too much reliance on disabled people's good will and voluntary effort.
- Information is not being communicated

- Governments appear rarely to acknowledge a need to resource DPO inclusion in the consultative process or to fully recognise their expertise
- In light of the aforementioned factors, the study recommends that:
 - Legislation should operate in a robust 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

Key Messages

- It is necessary to develop designs for disability statistics globally.
- Disability research in low-income countries should as far as possible be initiated and controlled by DPOs. This will ensure relevance and is a prerequisite for application of results.
- It is necessary to establish and develop collaboration between DPOs, researchers, national and regional authorities, and international organisations in order to build up disability research as a discipline in low-income countries.
- Application of disability research in low-income countries should be planned for and resources allocated for this purpose from the start of the project.
- Focal points for disability research should be identified both among relevant research institutions and DPOs.
- Long-term commitment to capacity building among DPOs and researchers to establish and develop a strategic working relationship between the two is needed from international donors and researchers.
- Researchers and institutions involved in disability research need to be sensitised to the particular challenges inherent in participatory research, with DPOs playing a leading role.

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

Has disability been mainstreamed into development cooperation?

Key Messages

Despite some impressive policy statements by national and international development agencies, disability has yet to be mainstreamed into development cooperation. This is true both centrally and in developing countries. The reasons for this are...

- broad-based institutional support within development agencies for disability mainstreaming has been weak or non-existent.
- there has been a general failure to communicate or monitor existing policies effectively.
- people continue to see disability as a medical question best left to professionals, so agency staff tend to ignore it
- there is little practical guidance on how disability can be mainstreamed.
- disability is not mentioned in the Millennium Development Goals
- no agency has adopted disability as an official cross-cutting issue
- the resources both financial and human which are being provided to take forward the disability agenda in all the agencies are derisory

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

Are disabled people’s voices from South and North being heard in the development process?

Key Messages

- DPOs and disabled people complained that donor funding came with unreasonable conditions
- DPOs indicated that their northern partners do not involve them in the planning process and their concerns are not being addressed.
- Overall the report found that disabled people’s were being heard in the North, but not in the South.

To address this it is recommended ...

- That the inclusion, integration and human rights of disabled people be more strongly promoted

- DPOs be given resources to implement activities and disseminate information on the African Decade for Person with Disabilities (1999 – 2009)
- Donors target DPOs for support, particularly programmes that enforce the rights disabled people and the development of grassroots initiatives that address poverty reduction, economic empowerment, and employment creation.
- Constructive partnership relationships be forged between DPOs in the North/ South and with donors.
- Disabled people and DPOs be fully involved in the planning, implementation, monitoring, and evaluation of disability initiatives.

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

Disability and conflict in emergency situations: focus on tsunami-affected areas

Key Messages

- DPOs had little involvement in post-tsunami reconstruction efforts, with European aid workers speaking on their behalf.
- There was no understanding of how inclusion and the social model of disability could be translated into practise.
- Consultation gave way to a pressure to spend money quickly.
- There was little evidence that DPOs and poor disabled people were recipients of aid in any form

To address these shortcoming ...

- More training is needed on the social model /disability rights and how it relates to all aspects of intervention
- More research, guidelines and training are needed to overcome barriers to implementing full inclusion
- The links between disability, development and discrimination and exclusion need to be explored and alliances made.
- There is a need to examine the effect on local DPOs when INGOs lead lobbying work.
- DPOs should be involved in the planning and conducting of needs assessments.
- Funding and capacity building support is needed for the disability movement to ensure that it is able to speak on its own behalf.

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

Situational analysis and assessment of education for children with disabilities in Bangladesh, South Asia (Nepal), East Asia (Vietnam) and South Africa

Key Messages

The educational systems from which disabled children should be able to benefit to some degree (special, integrated and inclusive education) in all the countries surveyed are lacking in their ability to address the needs of these children.

The reasons for this include the lack of:

- Government interest and support to implement existing policy
- Resources
- Technical skills
- Proper planning through actual situational analysis
- Coordination and mutual cooperation among departments of different ministries and professionals
- Communication and coordination between professionals and implementers
- Appropriate information
- Regional and international coordination and cooperation.

And above all negative attitudes towards disability issues which make devising and implementing effect educational policies problematic

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



Themes that recur throughout the research

Issues that have a direct impact on the development process include:

- implementing disability focused legislation;
- strengthening the capacity of DPOs to engage with international and national donors and institutions;
- re-thinking the new aid instruments and mechanisms so that consultation is truly inclusive;
- adopting the social model of disability in order to realise a human rights approach to development
- implementing, monitoring and evaluating policy

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';
- 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;
- Development agencies themselves must set an example on inclusion and equality by employing more disabled people as well as drawing on the experience and expertise of DPOs both in the North and South.



**This publication is also available at
www.disabilitykar.net for accessible
formats apply at address below.**

Pictures by



For more information contact:

Mark Harrison

SARC - Social Action Research Centre

Overseas Development Group

School of Development Studies

University of East Anglia

Norwich NR4 6TJ

mark.harrison@uea.ac.uk

Website: www.disabilityequality.org

