

DisabilityKaReport

Newsletter of the **Disability Knowledge and Research Programme** Issue 3 Summer 2005

Since taking over as programme director last September, I have tried to take the Disability KaR in a new direction.

The challenge has been to connect the practise of the programme to the principles of human rights and disability equality. This meant opening up the activities to disabled people from both the South and the North in a new way. To begin this process the policy project consulted members of the disability movement from Europe, Africa and Asia on the agenda for research. This engagement was deepened at the Malawi roundtable, where participants articulated a clear research agenda and principles for how disability research should be carried out (see p4).

It was this agenda that informed the commissioning of research in the policy project, the thematic research projects and the research prospectus. This process has produced an exciting set of collaborations between disabled researchers from across the globe. Based on the principles of emancipatory research, this work has produced a number of valuable, insightful reports which will be published over the next few months on the programme website, www.disabilitykar.net

The lessons from transforming the social relations of research – putting disabled people on top and professionals on tap – are applicable beyond disability research to similar work of other oppressed, marginalised groups. The challenge for those involved in development is to translate fine-sounding words about human rights and equality into practice that makes a real difference.

Mark Harrison, Programme Director
mark.harrison@uea.ac.uk

The Disability KaR Programme is part of DFID's broader programme to eliminate poverty in poor countries. The Overseas Development Group at the University of East Anglia, UK, and Healthlink Worldwide are managing the programme in partnership.

Disability KaR
Knowledge and Research

DFID

Contents

Sharing experiences, developing goals 2

Disability, poverty and the Millennium Development Goals... this was just one topic discussed at the three Disability KaR 'roundtable' forums held in Malawi, Cambodia and India

PRA by disabled people: the experience from rural Cambodia 6

Find out how a recent project trained disabled people to successfully lead a participatory rural assessment (PRA)

Mozambique DPOs and capacity building 8

What does capacity building mean to Mozambican DPOs and how do they view Northern initiatives to help? Research for the Disability KaR policy project sought to find out

Cross-border learning 9

A group from Rwanda's national DPO visited Uganda, to learn from their neighbour's experience in involving disabled people in policy making and other processes

Competition projects news 10

Websites have gone live, and new models of wheelchair are helping disabled people in harsh rural environments in Africa: three of the Disability KaR competition projects describe the culmination of their work

Programme advisors: an essential contribution ... 10

How the experience and advice of a team of dedicated advisors, including disabled, non-disabled, Southern and Northern voices, have benefited the Disability KaR Programme

Equal partners in research 11

The Programme's recently commissioned 'thematic research' has made a priority of putting disabled people in the driving seat

Resources 12

This issue's theme is empowering and involving disabled people in projects and policy-making

Abbreviations used in this newsletter

DFID	Department for International Development
DPO	Disabled people's organisation
MDG	Millennium Development Goal
KaR	Knowledge and Research
NGO	Non-government organisation
PRA	Participatory rural appraisal
PRSP	Poverty reduction strategy paper

Newsletter writing, editing and layout: Georgina Kyriacou

Sharing experiences, developing goals

Since November 2004, the Disability KaR 'roundtables' – three highly successful international discussion forums – have taken place in Africa and Asia. This article presents some of the main points raised and outcomes from activities

The three Disability KaR roundtables – facilitated discussion spaces for people to share their experiences and perspectives – took place in Malawi, India and Cambodia, organised by Healthlink Worldwide and a disabled people's or disability organisation in each country. Each had a theme but the idea was to allow the forums to develop according to the needs and priorities of participants, without a strict agenda. Before, during and after each roundtable, a moderated electronic discussion forum enabled an extended debate (see page 5).

Why were they held?

The roundtables were designed as one way to bridge the communication gap between stakeholders at grassroots level and policy makers – providing an opportunity for decision makers to hear and learn from the views and experiences of people with disabilities, disabled people's organisations and others. They were geared towards defining research priorities for the Disability KaR programme to take forward, looking at how to link disability policy and practice, in relation to mainstreaming disability in development, and the links between poverty and disability.

The roundtable themes were: disability, poverty and the Millennium Development Goals (roundtable 1); mainstreaming disability in development (roundtable 2); and mainstreaming in practice – the case of inclusive education (roundtable 3). Participants came from DPOs, NGOs, bi-lateral agencies, UN agencies and national governments.

Although each roundtable had a different theme and mix of participants, certain key issues came up across the three roundtables; for example, it was apparent that challenging the attitudes of society towards disability is considered of high importance,

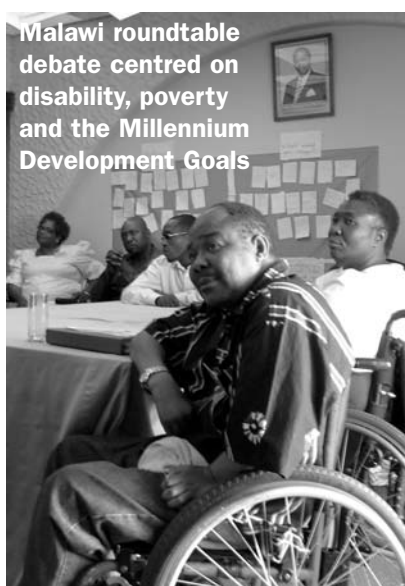


Photo: Healthlink Worldwide

as well as getting policy makers to recognise and address the challenges and issues facing disabled people. Other key discussion points from each forum are summarised below, followed by a selection of the main outputs.

Highlights

1. Disability, poverty and the Millennium Development Goals (MDGs) Lilongwe, Malawi, 2-4 November 2004

The Federation of Disability Organisations in Malawi (FEDOMA) hosted the first roundtable, which was attended by 39 participants

from Africa, India, South East Asia and Europe. Among them were representatives of government ministries, international NGOs, and regional, national and grassroots DPOs.

Participants identified a number of challenges to getting disability on the policy agenda. These included: disability being seen as a low priority by decision makers; lack of DPO capacity and unity; policies not being communicated down to the grassroots level; disability issues still being regarded in isolation.

A number of solutions were suggested, involving capacity building for DPOs, development of networks, increased lobbying, awareness raising of the effect of policies, and skills-building for DPOs. These suggestions were developed into a framework for action for use at national and international levels – see www.disabilitykar.net/docs/framework_for_action.doc

In discussions on the MDGs themselves, it became clear that although many participants had not previously thought about their work in relation to the MDGs, many DPOs were contributing to the achievement of the goals, and much of the work was already being done before the goals were 'created'. One participant said: "Take away the 'M'

View from a host DPO

Mussa Chiwaula of FEDOMA, Malawi, describes hosting the first roundtable as a 'learning and enriching experience which also put our name on the international map'. FEDOMA valued making new contacts and learning about what is happening in other countries, which they will try to 'localise' and apply to their situation. Mussa believes that preparing for the forum built FEDOMA's capacity to host events of this nature, and to advocate with results – the DPO has actively lobbied the government which has now passed new disability legislation. Finally, Mussa says that the involvement of disabled people in the organisation of events like this is vital.

and you are left with Development Goals – and we all work to those." People identified four MDGs in particular to which their work is directly contributing: Goal 1 – eradicate extreme poverty and hunger; Goal 2 – achieving universal primary education; Goal 3 – gender parity; and Goal 6 – combat HIV/AIDS, malaria and other diseases.

2. Mainstreaming disability Ahmedabad, India, 24-26 February 2005

The Blind People's Association (BPA) hosted the second roundtable, which was attended by 49 participants from South Asia, Africa and Europe, including the Chief Commissioner for Persons with Disabilities of the Indian government – so the potential was there to target the highest level of policy-maker.

Participants shared their experiences of mainstreaming and inclusion, both personal and from their work. Some of the challenges they identified were to do with: access and accessibility – one comment from the group was that "access is more than constructing a ramp at the entrance to a building", education and employment, attitudes and culture, and policy and legislation.

Suggested strategies to overcome these included: sensitisation and awareness-raising activities; capacity-building for government personnel involved in implementing disability legislation; inclusion of issues related to the education of disabled people in teacher training curricula and materials; skills-training for disabled people relevant to the employment market.

3. Mainstreaming disability in practice: the case of inclusive education Phnom Penh, Cambodia, 4-6 May 2005

The third and final roundtable was hosted by Cambodia's Disability Action

Council (DAC) and drew 64 participants, including members of the inclusive education team within the Cambodia Ministry of Education, Youth and Sports, parents of children with disabilities and DPOs.

Participants shared practical examples of working with inclusive education in resource-poor settings. Among issues discussed were the appropriateness of inclusive education for all children with disabilities, and the role of special schools. The group made the following key recommendations for implementing inclusive education:

- Capacity development should not be limited to education. For example, in Laos capacity development has involved the health sector enabling children with disabilities to access key health services.
- Life skills are essential to all children and should be included in the general curriculum.

cont. next page

From the participants**Lobbying and awareness raising**

"DWSO [Disabled Women Support Organisation] has started to work with government to fight for inclusion of people with disabilities in the development process. After the Malawi roundtable, we managed to lobby a number of women's organisations in Zimbabwe for networking purposes." *Gladys Charowa, DWSO, Zimbabwe*

"The most important action will be ... networking with non-disability development organisations to mainstream disability issues as this will remove the barriers, break the negative attitude and facilitate inclusion of disability as part and parcel of any development programme." *Kuhu Das, Association for Women with Disabilities (AWWD), India*

"I have only just become disabled and I have been concentrating on my rehabilitation. I now see that I can help create awareness of others as well." *Anon*

"It opened my eyes to the other ways of advocating for the rights of the disabled; it exposed me to disability issues at an international level." *Anon*

Exchanging information, making new contacts

"We have made contacts with an organisation promoting dance and performing arts among people with disabilities and will coordinate to introduce art and movement therapy for children with cerebral palsy, autism and intellectual disability." *Bhoomikumar Jegannathan, Centre for Child Mental Health, Cambodia*

Insight into lives of disabled people

"I was amazed at the depth of [a blind colleague's] participatory skill and content in the group and plenary discussions. I also discovered a lot of persons with disabilities, their qualities enthused me a lot." *Muhammad Hilaluddin, mainstream human rights activist, Bangladesh*

Inclusive education

"Parents feel that they are not listened to and this was demonstrated at the roundtable where one of the parents present passionately argued her case with ministry officials ... One of the aspects which will receive [our] greater attention in future will be to strengthen the involvement of parents in the development of programme activities." *Imtiaz Mohammed, Leonard Cheshire, India*

DisabilityKaReport



Photo: Healthlink Worldwide

Participants in the third roundtable visited Krousar Thmey school for deaf children in Cambodia

- Awareness raising among teachers, parents and children should be done in conjunction with the development and implementation of any policy.
- Working with parents is essential to promote positive attitudes and perceptions about the abilities of children with disabilities.
- Teacher training should attempt to reach a variety of teachers with different backgrounds and experience.

Main outputs from the roundtables

1. The Malawi roundtable **identified research areas** that would help support their work; the Disability KaR programme's 'Research Prospectus' has been based on their list. Ten areas for priority were identified – see table, right. The participants also created the following list of **guiding principles for research and policy development**:

- 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 participants
- 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

2. Participants in India produced a **petition about the Millennium Development Goals (MDGs) and disability to be sent to the United Nations**. The petition suggests modifications to the MDGs, stating: 'The sheer number of Persons with

4 www.disabilitykar.net

Disabilities in developing and/or poor countries makes them the largest group of people vulnerable to extreme poverty and hunger. We urge the UN to acknowledge that disability is one of the key indicators of poverty.' You can read the full draft petition at www.disabilitykar.net/docs/petition.doc, where there are also details of how you can comment on it. It has also been posted on the Disability India website, where up to July 19 there had been 320 signatures – www.disabilityindia.org/mdgsign.cfm

3. A checklist of suggestions of **how to engage mainstream development organisations in disability issues** was also produced at the India forum. The suggested principles are:

1. See disability as a broad development issue
2. Converse with development organisations in a language that they understand. For example, when talking to the World Bank talk about economics, when talking to DFID talk about the MDGs
3. Identify key entry points and contacts
4. Be specific – use evidence (qualitative and

Areas of priority for research, identified at the Malawi roundtable

Research priority	Specific research ideas
Poverty and disability	How disabled people engage in the PRSP process
Legislation and poverty	How disabled people engage in the PRSP process
Development aid and DPOs	How effective development aid is; trends in donor funding in relation to disability
Data collection	Appropriate methods of data collection e.g. national census
Prevention of disability	The role of DPOs in disability prevention programmes
Education	The current shortfalls in education systems; the impact of inclusive education; differences between specialised and inclusive education
Humanitarian situations and conflict	The relevance of 'mine action' programmes on the disability sector; the extent that post conflict strategies and humanitarian aid deal with the needs of disabled people
HIV and AIDS	Survey of literature; the impact of HIV and AIDS on disabled people; engagement of DPOs in campaigns against HIV and AIDS
DPOs	Lessons to be learnt from other liberation movements
Transport	Barriers faced by disabled people in their daily lives
Others	Demonstration projects in health, education and transport that are inclusive of disabled peoples needs

quantitative) that is relevant to the context, and document actual experiences

5. Adopt a broad-based approach, demonstrating how inclusion will benefit all society
6. Engage with generalist development networks
7. Identify strategic partners and strategic opportunities
8. Be positive, identify areas where you can support the development organisation, do not only criticise it
9. Document and disseminate models of inclusion and the process
10. Focus on the things that unite, not the things that divide.

Participants determined the key barrier as disability being seen as a separate 'special' sector requiring a technical and welfare approach.

4. Indicators for identifying whether disability has been mainstreamed were produced at the India roundtable, for both the micro and macro levels.

Micro-level indicators include:

- People with disabilities included in local governance structures
- Numbers of people with disabilities represented in the target communities of NGOs match the demographic profile of the country or community
- Majority of girls, boys, women and men with disabilities receive a quality education in mainstream, local schools and institutions (except those who need special education)

Macro-level indicators include:

- People with disabilities secure employment on merit, not as a result of quotas
- Public buildings, spaces and transport are accessible for all persons with all types of impairments
- Teacher training includes components on educating children with disabilities
- All ministries have a budget allocation that reflects the demography of people with disabilities and utilises this allocation effectively

For the full list, go to www.disabilitykar.net/docs/indicators.doc

5. The Cambodia roundtable produced **good practice guidelines for inclusive education**, which looked at issues of teacher training (from awareness raising to curriculum development), the physical aspects of the learning environment, making the learning environment appropriate for all, involving parents, peer education (students teaching

Participating remotely: the roundtable 'e-forum'

Since the e-forum started life in October 2004, organised to support the roundtables, over 550 messages have been posted to more than 150 people from DPOs, NGOs, bi-lateral agencies and national governments. As well as the three themes of the roundtables, people have discussed the content of a petition to the United Nations and a review of India's National Policy on People with Disabilities, as well as highlighting global events, research papers, useful resources and the sharing of experiences between countries.

Gladys Charowa of the Disabled Women Support Organisation (DWSO) in Zimbabwe, has been a keen contributor. She used the forum to share her experiences of what it is like to be a woman running a small DPO. She has initiated and taken part in discussions on the Millennium Development Goals, and equality and gender, and has shared her research on HIV and AIDS and disability, and information on the links between poverty and disability. Gladys commented: "The e-forum has allowed me to share information, experiences and ideas on disability. All the contributions have made DWSO grow in its understanding of disability issues."

The e-forum will remain open over the summer and can be accessed at: www.dgroups.org/groups/disabilityKaR. For more information please email: maniam.n@healthlink.org.uk

each other), encouraging study tours and exchange visits, assessment and evaluation checklists, adaptive devices and aids for children with disabilities to enable their education, collaboration and exchange of experiences and learning, and linking education and community based rehabilitation.

For the full list see www.disabilitykar.net/docs/ie_good_practice.doc

6. A framework for action to good implementation of inclusive education was also produced at the Cambodia roundtable. The titles of the five steps, which each have explanatory notes, are:

- Step I** – Be aware of good frameworks on which to base work
- Step II** – Develop and review policy (national and provincial)
- Step III** – Develop a strategic plan
- Step IV** – Let people know the importance of the implementation of the plan
- Step V** – Just do it!! (implementation)

The contributors noted that Steps I to III require the participation of policy-makers, teachers, principals, donors, parents, children and people with disabilities, and Steps III to V require regular meetings by stakeholders to monitor and evaluate and research the implementation of inclusive education. Throughout the development of policy and legislation transparency and good governance are vital. Steps I to V form a cyclical process whereby what is learnt over the cycle may lead to revisions in policy and strategy to take account of experience and lessons.

For the full list, see www.disabilitykar.net/docs/ie_framework.doc

PRA by disabled people:

A Cambodian NGO recently piloted a project in which disabled people controlled a participatory community assessment (PRA), in a country where disabled voices are rarely heard. Steve Harknett describes the project's challenges and successes.

Disabled people are among the most marginalised, voiceless people in any society, but particularly so in Cambodia. Unlike many developing countries, the Cambodian disability sector is still dominated by organisations *for* rather than *of* disabled people. The national disability rights movement is in its infancy and no disability legislation has been passed. Disabled people are traditionally seen as passive receivers of aid, a belief which persists among many NGOs, which plan and design disability programmes with little input from disabled people themselves.

This is a problem that has been recognised by Disability Development Services Pursat (DDSP), which runs a community-based rehabilitation (CBR) project. In the past DDSP has carried out village-level participatory rural appraisals (PRAs) which were designed and implemented by its staff and local government officials, with disabled people's role limited to consultation. Although the PRAs succeeded in getting disabled people's input into the CBR project design, they did not empower disabled people as they were still the objects of the research rather than participants or leaders of it.

Disabled people at the project helm

In response to this, DDSP embarked upon a new PRA research project in February 2005, supported by the Disability KaR Programme. The project aimed to pilot a participatory

community assessment controlled by disabled people themselves. This, it was hoped, would build disabled people's capacity in community development skills, challenge community attitudes towards them, and promote their participation within DDSP.

The project involved training the team in PRA methods so they could plan fieldwork (e.g. make decisions about research topics and tools) and carry out short PRA exercises in three villages. After each village PRA, the team also analysed and presented the results, and evaluated the process. Lessons drawn from the project are discussed below.

Training inexperienced disabled people

During the three-day PRA training, the team learnt about several PRA tools and made a plan for using them in the field. The following points contributed to the success of the training workshop:

- **Focus on confidence-building.**

The very term 'training' can be threatening to uneducated people who imagine it as formal learning using literacy skills which they do not have. The training was therefore termed a 'meeting' and other alien terminology such as PRA was avoided.

Other steps taken to build participants' confidence were: keeping the training group small to reduce shyness; starting the training with a simple, fun activity like 'picture introductions' (participants drawing pictures and using them to talk about their lives); being realistic in what



Photo: Steve Harknett

Problem-ranking exercise carried out by disabled villagers. Disabled PRA facilitators help a boy participate (right)

the participants could learn – PRA tools needing advanced literacy, group facilitation or presentation skills were avoided; creating a comfortable environment – e.g. participants and facilitators sat on the floor in the traditional Cambodian way, in a private house rather than an office.

- **Awareness by the facilitator of the participants' level,** and use of appropriate communication methods. Verbal and pictorial, rather than written, methods were used, with frequent reviews and repetition, at a pace consistent with that of the participants' learning.
- **Consideration of physical accessibility and personal needs.**
- **Not assuming** that the disabled people automatically had solidarity with one another or had comprehensive knowledge of all types of disability. The training included sessions on types of disability and respect for and understanding of all disabled people. Emphasis was put on including marginalised groups such as people with visual, hearing and learning difficulties, people with mental health problems, disabled women,

experience from rural Cambodia

children and elderly people.

● **Including participatory monitoring of the training** throughout, and acting on any problems/ideas raised by the participants.

Appropriate PRA tools

The PRAs used many ways to collect information about disabled people in the community. Due to lack of experience, low educational level and the short time allowed for training, the disabled team members found some tools easier to use than others. **Those they found easy to use were:**

- Pictorial methods – e.g. an illustrated household wealth surveying tool was developed and used to compare the wealth (measured by ownership of cows, pigs, TV, etc.) of households with and without a disabled person. Pictures were also used in PRA presentations, e.g. illustrated graphs showing prevalence of types of disability. Illiterate people can understand pictures more easily than words, although producing the pictures was difficult – people who are illiterate do not generally have experience in drawing, so time was needed for the team to practice, in order to produce sufficiently useful pictures.

- Activities directly and concretely related to their daily lives, e.g. ranking disabled people's income-generating activities and discussing their daily activities.

The tools the team found difficult included:

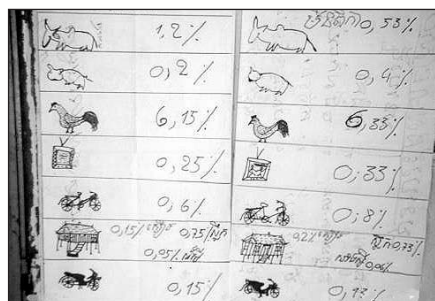
- Activities involving advanced facilitation skills. One exercise

involved developing solutions to disabled people's problems. Villagers typically responded with a list of things they wanted NGOs to give them, and facilitation was needed to get the villagers to think of ways in which the community could help themselves. The disabled team members, sharing the same mind-set as the villagers, were unable to do this.

- Activities involving literacy and numeracy skills, e.g. using written questionnaires and calculating percentages from wealth-ranking data.

- Role-play – the team-members were unfamiliar with this and felt embarrassed.

Photo: Steve Harknett



The team's pictorial presentation of the comparative wealth of households with and without a disabled member

- Talking to people in authority in the community, e.g. teachers and village chiefs, as they did not have experience in this and felt inhibited.

Enabling all disabled people to participate

In the field, the team were constantly reminded to try to include all disabled people in PRA activities and to overcome barriers to their participation – both physically attending the

meeting and also joining in actively.

Examples of good practice included:

- Seating team members among participants in meetings and giving additional encouragement or explanation when they observed that this was needed.

- Helping people with hearing impairments, e.g. by asking family members to communicate with gestures, and inviting people to sit at the front so they could hear more easily or lip-read.

- Using simple language and repeating verbal instructions. The facilitator asked the participants questions to check their understanding.

- Keeping written exercises to a minimum because of low literacy. Where written flipcharts were used, only short key-points were written, using large, clear letters, and they were accompanied with clear verbal explanations.

- Visiting disabled people absent from meetings or who sent a family member to attend on their behalf (which is common practice in Cambodia) at their home. Sometimes they were absent for good reasons, but often it was due to not receiving the information (perhaps due to marginalisation in the village), transport problems or behavioural problems, which the PRA team could help address.

- Acting on information: e.g. one village chief said he had heard of a man with severe moving difficulties living far away, but had never met him. The team, after a lengthy search, tracked him down and brought him to a meeting by motorbike. Many villagers had never seen him before. In another village the aunt and uncle of a severely disabled orphan – who were very unmotivated and neglected the child as he is not their own – were given encouragement and help with transport to come to the meeting.

DisabilityKaReport

Impact of the project

The research project was pioneering in Cambodia as it put rural, inexperienced, disabled people right at the centre of the development process. The project had an impact on the disabled PRA team members themselves, their communities, DDSP and the disability sector in Cambodia in general, as described below.

Disabled team members: the five disabled people gained skills, experience and increased confidence in doing PRA community assessment. They also learnt about different types of disability, and gained a wider understanding of different disabled people's situations.

Their communities: villagers were able to see disabled people playing an important role in community development. There

was some surprise among villagers that the woman with learning difficulties was playing such a role, and among her family, who had formerly considered her as quite useless.

DDSP: the project contributed to a change in attitude among DDSP staff as disabled people were doing a task that was normally theirs. It was the first time that DDSP staff had worked alongside their beneficiaries and it challenged the traditional NGO-client relationship. It is hoped that in future PRAs, DDSP will include representation from disabled people.

Disability sector: the research project involved two other NGOs in Cambodia, Handicap International Belgium and Landmine Disability Support, who, like DDSP, were experiencing difficulties in including rural

disabled people in community surveying and project designing. Results from this research project will be shared with these NGOs and the rest of the disability sector in Cambodia. It is hoped that this will encourage changes in practice, increasing disabled people's participation in and control of development processes such as community assessment and project design, to ensure that projects more fully meet their needs.

Steve Harknett is Advisor to Disability Development Services Pursat (DDSP), a Cambodian NGO that supports a wide range of initiatives for and with disabled people. For more information, contact Steve Harknett or Keo Sophat at ddsp@Cambodiatic.org, PO Box 9206, Pursat, Cambodia

Mozambique DPOs and capacity building

The situation of disabled people in Mozambique is characterised by extreme levels of poverty, low levels of education, illiteracy and low self-esteem. A recent research project for Disability KaR examined the role and effectiveness of DPO capacity-building initiatives in the country.

Contrasting perspectives

For Mozambican DPOs, capacity building means strengthening their organisations to be effective in their work and to achieve results for their members. They want capacity building to increase their skills to plan, implement, monitor and evaluate their work. However, technical support needs to be accompanied by financial resourcing, so that DPOs can implement programmes and projects to gain experience in administering their affairs.

DPOs see some of their

Northern NGO partners as giving limited technical support, without paying attention to how organisations survive from day to day. Yet some Northern NGO partners are recognised as striving to provide more balanced forms of support.

The over-reliance on Northern, rather than local, experts by their Northern NGO partners is seen as unhelpful to DPOs, who prefer the use of local resource people for training inputs. DPOs also see an unequal distribution of power with their Northern NGO partners raising money from the North in the name of disability but not discussing openly how it should be spent. DPOs see themselves being treated more like clients and objects, rather than as the primary bodies who legitimise outside intervention in the sector in the first place.

However, Northern DPOs are appreciated for their empowering

attitude, treating their Southern counterparts as equals, whom they respect and listen to. The shared values of the disability movement contribute to this more equal relationship.

As for the government Ministry responsible for disability issues, this is seen as a helpless spectator. It has no resources for disability work, and actually seeks funding from the same few agencies who are involved with disability work in Mozambique.

Commitment to open and frank discussions and experience sharing on an on-going basis among Southern DPOs themselves is now required. The DPO workshop that was held during the second visit of the research was a response to this need, and the organisations greatly valued its very frank exchanges.

**Jabulani Ncube,
Independent consultant**

Cross-border learning

In May 2005 a delegation from Rwanda's national DPO, the Federation des Associations et Centres pour Handicapés au Rwanda¹ (FACHR), made a learning visit to umbrella organisation the National Union of Disabled Persons in Uganda (NUDIPU).

The visit was made following recommendations from research undertaken in Rwanda by the Disability KaR Policy Officer².

One of the conclusions of this research was that Rwanda's disability sector was being undermined by a lack of coordination within government ministries and with and between civil society actors. FACHR was recognised as being a suitable organisation to lead such a coordination, but needing substantial development, capacity-building and support to do so. It was also concluded that FACHR and other Rwandan DPOs need to be strengthened to be able to advocate for the rights of disabled people with government, donors and society as a whole.

Prompted by these observations, FACHR was facilitated by DFID and Disability KaR to visit neighbouring Uganda

to learn from NUDIPU's successful ways of working, in a country that is recognised as having an advanced disability movement.

The study tour was divided into three parts, enabling FACHR to gain insight into the structure and ways of working of NUDIPU, to meet with MPs representing disabled people, and visit a number of DPOs.

Observations

The Rwandan delegates noted how NUDIPU members find solidarity by working as a united group. The visitors saw the inclusion of disabled people into the Ugandan constitution as NUDIPU's most significant achievement, and recognised the strength of the Ugandan group's lobbying and the slogan 'Nothing for us without us', which have enabled disabled people's inclusion in development



Photo: Bernard Bagweneza

The Rwandan visitors meet members of the Ugandan National Association of Physically Disabled Persons

programming, decision making and policy-making and legislation.

The visitors drew a number of recommendations to take home to Rwanda, including: disabled people should take part in decision-making; mass media should be used to sensitise the public; associations should be set up for different disabilities and organised on a national level; FACHR should be independent and look for donors who have the same understanding of disability issues that it has itself; education should be prioritised for people with all kinds of disability; in order to become united, the disability movement in Rwanda should be structured as 'one family' with FACHR at the centre.

Notes

1. Federation of associations and centres for disabled people in Rwanda
2. Philippa Thomas, assisted by Bernard Bagweneza

To read the full report on the Rwandan research, visit www.disabilitykar.net/pdfs/rwanda_ex.pdf

The disability movement in Uganda

Uganda has a highly advanced disability movement, expansive disability legislation, and representation of disabled people at all levels of government – with NUDIPU itself having five seats in Parliament.

NUDIPU, formed in 1987, is very well established. It includes all kinds of disability and gets its voice heard throughout Uganda by being represented from village to national level. NUDIPU is frequently consulted by the government on matters related to disability.

Firmly integrated into Uganda's disability movement, NUDIPU's aims are to bring disabled people together, create a common and

unified voice, break traditional divisions built along medical lines, raise awareness of problems and issues affecting disabled people and mobilise their efforts in developing strategies and implementing action to address their needs. It advocates for the equalisation of rights and opportunities for disabled people, and helps its member associations to get funding.

The organisation is very much inspired by the slogan 'Nothing for us without us', with planning, managing, implementing and monitoring of all its programmes done by and for disabled people. For NUDIPU, disability is a human rights issue.

Competition projects news

Completion of wheelchair knowledge sharing project

Motivation's Disability KaR funded project is now complete: it has included the design of a new three-wheel wheelchair to cope with harsh rural environments, and a hand-propelled tricycle that enables the user to travel greater distances independently. The requirements of children with

more complex supportive seating needs have been researched, as well as the possibility of replicating the Tanzanian based Wheelchair Technologists Training Course in Central America.

A practical 'Wheelchair Service Guide for Low Income Countries' has been published as part of the project, and is being distributed across Africa and internationally.

Disability information

Source's CD-ROM 'The Disability Convention – Making it Work', is now available (see p12). It was launched at a meeting of the UN Convention and has been sent to DPOs and disability NGOs in Asia, Latin America and Africa.

The redesigned Source website www.asksource.info went live in May 2005; new features include 'Add a resource', 'Support for resource centres', the 'Key topic' areas, and an improved search interface for the databases. The

new design is fully accessible to disabled users and loads quickly for users with slow connections.

Key lists of essential resources on disability topics such as 'Mainstreaming and disability' have been also produced.

Health information systems

Baobab Health Partnership has now installed 57 touchscreen clinical workstations have now been installed in Kamuzu (Lilongwe) Central Hospital, Malawi, spanning a number of departments. The number of patients registered now exceeds 205,000. The renovation of the Information Systems building was completed in January 2005 and it is now fully functional.

The Ministry of Health sees the value of the Patient Management Information System (PMIS) as a tool for improving patient care while transparently collecting valuable data needed to support management and public health initiatives. Expansion of the PMIS to a hospital in Blantyre will start later in 2005.



Photo: Motivation

Fetching water with the aid of Motivation's hand-propelled tricycle

Programme advisors: an essential contribution

The current Disability KaR Programme Advisory Group (PAG) was established in June 2004, following a review of the advisory structure of the programme. Ray Lang and AK Dube, both well known and respected for their work on disability, advised on the composition, mandate and responsibilities of a PAG, and a group of seven voting members was formed, of which four are disabled people.

AK Dube says of involving people from developing countries in the Programme's decision-making: "I am quite confident that this objective was achieved" He explains: "It is important that we take into account technical expertise from the South in any future strategies that address

the needs of disabled people in the South. It is essential to build and sustain people-to-people relationships between the North and South on issues related to disability and sharing of expertise."

Another PAG member, Setareki Macanawai, concurs: "As someone from a developing country ... I had the opportunity to share my views, express my concerns and declare that we, especially Southern DPOs, can be potential partners to Northern DPOs in addressing our development needs, and [take] the lead to move our issues forward."

The PAG has met twice since June 2004, and once by teleconference, also making ongoing input in the form of

feedback on written outputs of the Programme. During the final meeting in May 2005 the managers of the commissioned research (see p. 11) presented their preliminary research findings. The PAG commented first hand and debated some of the key points raised. They also discussed the research with Simon Anderson from DFID's Central Research Department, thereby feeding directly into DFID's consultation on the future of its disability research strategy.

The PAG has played a significant role in providing advice and expertise to the programme. This has been appreciated and the Programme would like to thank all the PAG members for their time and support.

Equal partners in research

Programme Director Mark Harrison presents an overview of Disability KaR's 'thematic research agenda', and the concepts essential to its delivery.

Since taking over as Programme Director in September 2004 my priority, together with that of the Disability KaR team, has been to open up the Programme to greater involvement of disabled people from the South and the North. The aim was to ensure that work done under the Programme reflected a genuine emancipatory research approach, with disabled people taking a leading rather than a supporting role.

It was the Programme's belief that this would not only result in high quality outputs, but also ones which, because they were firmly grounded in lived experience, would be directly relevant to the concerns of disabled people. In turn it would be more likely that any policy and practice following from the research would be both sustainable and positively transforming.

First steps: consultation

To start the process, representatives of Disabled People's International (DPI) and individual disabled people's organisations (DPOs) were consulted on what the research agenda should encompass. Further consultation occurred at the Malawi roundtable, which brought together many Southern DPOs and other stakeholders (see pages 2 and 4). A key output of this roundtable was a detailed list of research topics and, as importantly, a model for how the work should be done.

As a result of these meetings, four short-term research projects were directly commissioned from Southern-based disabled

researchers by the policy project (including the research in Cambodia, p 6, and Mozambique, p 8). Nine other pieces of research were incorporated into a thematic research prospectus.

Choosing the projects

This prospectus was sent out to disability organisations and researchers worldwide. The criteria for judging proposals were based on quality, the involvement of disabled people as researchers and collaborations between Southern- and Northern-based researchers. Seven research projects were commissioned, all led by or involving disabled people as researchers.

Of central importance was involving disabled people from the South as equal partners in either leading the research or as members of the research teams. So often, as subsequent research in Mozambique and South Africa discovered, DPOs are used as bit-part players or sub-contractors in Northern agencies' agendas. The Disability KaR Programme has tried to model a new way of working, which enables disabled people to set the research agenda through upstream engagement, puts disabled people in the driving seat in the research process and, as active participants, builds their research capacity from the bottom up. This is what we understand as capacity building, empowerment and emancipatory research.

Of course, the proof of the effectiveness of our approach has to be judged by the quality of the research, how the process

itself has brought disabled people together internationally and the way in which research capacity of DPOs has been strengthened.

Just the beginning...

One thing is clear: what we have attempted to do in the Disability KaR Programme is only a first step in addressing the traditional methods by which disability and development research is carried out. There remains a great deal yet to do. The research capacity of DPOs must be increased in a sustained manner. Power relations between researchers and the researched need to be continually challenged. And finally, as Mike Oliver¹ has said, "...it seems ... that [applied or action research approaches] are concerned to allow previously excluded groups to be included in the game as it is, whereas emancipatory strategies are concerned about both conceptualising and creating a different game, where no one is excluded in the first place."

Formulating this 'different game' is essential if research on disability and development is to become an effective tool in bringing disabled people and their concerns fully into the development mainstream.

Note

1. Mike Oliver is Professor of Disability Studies, University of Greenwich, London

To read the thematic research reports, visit www.disabilitykar.net/programme/res.html

To contact Mark Harrison, email mark.harrison@uea.ac.uk

Resources



These resources look at the empowerment and involvement of disabled people in projects and policy-making. All are free of charge unless stated otherwise. For more resources, visit the Source International Information Centre: www.asksource.info

● *Beyond de-institutionalisation: the unsteady transition towards an enabling system in South East Europe*, Adams, Lisa, Axelsson, C and Granier P, Belgrade: Handicap International Regional Office for South East Europe, 2004, 208 p, ill.

Addresses the unsteady transition of the Balkan countries into a system that enables and empowers disabled people at all levels. Available from: Handicap International, Regional Office for South East Europe, Vojvode Vlahovica 12, 11000 Belgrade, Serbia.

Available online at: www.disabilitymonitorsee.org/indexe.htm

● *Brief overview of the mandate of the African Decade for Disabled Persons (ADDP) Secretariat*, Cape Town: ADDP Secretariat, (no date) 8 p. Available from: ADDP Secretariat, Po Box 587, Cape Town 8000, South Africa Website: www.africandecade.org.za Fax: +27 21 422 0861. **Available online at:** www.disability.dk/site/viewdoc.php?doc_id=1348

● *CBR: a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities – joint position paper 2004* World Health Organization (WHO), International Labour Office (ILO) and United Nations Educational, Scientific and Cultural Organization (UNESCO) (et al), Geneva: WHO, 2004, 31 p. ISBN: 92 4 159238 9 This paper underlines that community-based rehabilitation is a strategy promoting multi-sectoral collaboration to reach different community groups. Available from: WHO Marketing and Dissemination, CH-1211 Geneva 27, Switzerland Fax: +41 22 791 3111 E-mail: bookorders@who.int publications@who.int Online bookshop: <http://bookorders.who.int> **Available online at:** <http://unesdoc.unesco.org/images/0013/001377/137716e.pdf>

● *The disability dimension in EU country strategy papers and national indicative programmes for ACP [African-Caribbean Pacific] countries: how to ensure that the socio-economic integration of persons with disabilities is part of the CSP process*, Christian Blind Mission International Brussels: 2004, 48 p.

A paper prepared as a guidance for the delegations and offices of the EU to include disabled people in their policies. Available from: Christian Blind Mission (CBM), Galeries de la Toison d'Or, 29 Chaussée d'Ixelles 393/26, 1050 Brussels, Belgium Website: www.cbmi.org **Available online at:** http://europa.eu.int/comm/development/body/theme/human_social/docs/health/04-04_disability_analysis_CSP.pdf

● *The Disability Convention – Making it work* CD-ROM: Source, Handicap International, and the International Disability and Development Consortium (IDDC), 2005

New CD-ROM created for and launched at the Fifth Ad Hoc meeting for the United Nations Convention of the Rights of Persons with Disabilities, in New York in February 2005. It contains 90 resources on disability and development, designed to help aid agencies and development organisations to mainstream disability into poverty reduction strategies, promoting the inclusion of disabled people in international development through the recognition and strengthening of human rights.



It also aims to spread experience and stimulate an international information exchange. The CD-ROM is available on request (while stocks last) from Stefan Lorenzkowski – please email: stefan.lorenzkowski@hi-uk.org.

Available online at: www.iddc.org.uk/cdrom

● *Disabilities Information Resources (DINF) Japan*: Japanese Society for Rehabilitation of Persons with Disabilities (regularly updated) Useful source of online documentation for the Asia Pacific region. Contains materials on community-based rehabilitation and full text versions of major policy documents, including all those relating to the Asia Pacific Decade of Disabled Persons. Available in English or Japanese.

Website: www.dinf.ne.jp/doc/english/index_e.html

● *Participation of organisations and partners for persons with disabilities in the PEAP 2003 Revision*, Ddamulira, D. (Commissioned by NUDIPU, USDC and ADD), July 2003 The Ugandan government invited stakeholders including DPOs to participate in the revision of its Poverty Eradication Action Plan (PEAP), 2003. This report presents proposals from DPOs for the revision, to guide policy makers and stakeholders in making practical policy interventions that will reduce the poverty of disabled people but most importantly recognise the need to integrate them into all of Uganda's development processes. **Available online at:** www.disabilitykar.net/docs/recommendations_nudipu.doc

● *Towards equality: creation of the disability movement in Central Asia*, Katsui, H., Helsinki: University of Helsinki, 2005 207 p ill. ISBN: 952-10-2256-6; 952-10-2257-4

Study focusing on a political approach to civil society in the field of disability. It shows how disabled people can organise themselves and make themselves heard. Available from: University of Helsinki, P.O. Box 33 (Yliopistonkatu 4), FI-00014 University of Helsinki, Finland. **Available online at:** <http://ethesis.helsinki.fi/julkaisut/val/sospo/vk/katsui/>