

TheKaReport

Newsletter of the Disability Knowledge and Research Programme Issue 1 Spring 2004

The Disability KaR programme has been launched, and with it comes the first issue of its newsletter, the KaReport.

This DFID-funded programme seeks to generate high-quality research on issues related to disability and to use this to influence development policy and practice. It does this through a combination of awarding projects through open competition and commissioning specific research.

The KaReport provides a forum for the sharing of learning, both from the six competition projects that are part of this phase of the programme, and from other relevant projects and research. As part of the programme's knowledge and communications component, the newsletter links with the programme's website, the electronic communications group and the upcoming regional round-table meetings.

This first issue takes a look at the lessons learned from the programme's first phase — Disability and Healthcare Technology — which ran from 2000 to 2003, and the pronounced link between disability and poverty. Other articles include reports of relevant studies, recent disability-related conferences and workshops, and a list of resources.

More information on the programme can be found at www.disabilitykar.net. This site also provides signposting and links to other useful materials and websites.

We hope that the newsletter is of interest; please send any comments to the editor (see opposite).

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.

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Disability: a key development issue

The Knowledge and Research Programme on Disability and Healthcare Technology was launched in 2000. As the second phase begins – called Disability Knowledge and Research – this issue of the KaReport looks back at the first: its achievements, the lessons learned and what these mean for the future.

The UK Department for International Development (DFID) launched the Knowledge and Research (KaR) Programme on Disability and Healthcare Technology in September 2000. Jointly managed by Healthlink Worldwide and GIC Ltd, the first phase of the programme funded 17 projects in Africa and Asia up to March 2003. The aim of this phase was to improve healthcare technologies and infrastructure for poor people, minimise the detrimental effects of disability on their lives, and stimulate and share learning and knowledge.

The second phase beginning now has a greater focus on disability and aims to address, through policy development, the connections between disability, poverty and development.

Phase one has many lessons, both project-related and programmatic, to inform the second phase and the broader debate on disability and development.

Technology in action

Many of the initiatives in KaR phase one focused on practical technological solutions to issues of disability and healthcare provision. Three examples from

the first round of projects can be used to illustrate the successful application of technology. (Detailed summaries of each of the projects and lessons learned can be found in the *Learning in practice* pack¹.)

The KaR programme funded research in Ghana and India undertaken by UK-based Adaptive Eyecare Ltd. This research showed that poor vision is a major block to learning, and a significant

reason why pupils drop out of school and fail to become literate. The remedy proved to be relatively simple: spectacles with adaptive lenses that wearers can quickly and easily adjust

themselves. Without the need for highly trained opticians, this is a straightforward, cost-effective solution that gives people direct control over their visual impairment.

“To me, a plastic calliper is the feeling of freedom from my impairment ... [It] is easy to wear, comfortable, gives more mobility and is good looking — I am no longer ashamed to wear it!”

Kuhu Das, West Bengal

In India, a KaR-funded collaboration between a disability organisation, Mobility India, and a large plastics manufacturer, Abhyanta Plastics, led to the development of prefabricated, mass-produced knee-ankle-foot orthoses (KAFOs), to address the many problems associated with traditional metal callipers.

One user, Kuhu Das of the Association for Women with Disabilities, West Bengal, reports: “To me, a plastic calliper is the feeling of freedom from my impairment ... [It] is easy to wear, comfortable, gives more mobility and is good looking — I am no longer ashamed to wear it!”

As a third example, a KaR



Applying technology: prefabricating new knee-ankle-foot orthoses (Photo: Mobility India)

project in Africa funded UK-based organisation Motivation to develop a Wheelchair Technologists' Training Course — the first in the world. The course aimed at building local capacity to design, produce and maintain wheelchairs, in order to give disabled people access to low-cost, appropriate wheelchairs.

Lucia Shayo, 12, of Kibosho, Tanzania, was given a chair by Motivation two years ago. She says: "It's made a big difference to me... Now I can easily visit my friends as well as attend school."

Graduates of the training course also sing its praises. "With the new skill I hope to manufacture low-cost wheelchairs which will benefit some of the poorest members of our communities," says Zimbabwean Emmanuel Majole, who is himself disabled.

Communicating knowledge

Another important part of KaR phase one was the documentation and communication of disability-related information. Healthlink Worldwide and its partners set up a physical resource centre and used information and knowledge management tools such as web-based databases with the aim of increasing people's access to information on international good practice on disability.

Teaching-aids At Low Cost (TALC) produced and distributed free CD-ROMs containing health and training information for health workers in the South. Studies have shown that while many health workers in the South do not have Internet access, they can use CD-ROMs. This technology is also relatively cheap to produce and distribute.

"With the new skill I hope to manufacture low-cost wheelchairs which will benefit some of the poorest members of our communities."

Emmanuel Majole, Zimbabwe



12-year-old Tanzanian Lucia Shayo, seated in her Motivation wheelchair, with her classmates (Photo: Motivation)

Lessons learned

KaR Programme Director Roger Drew identifies three major lessons from phase one.

First, the programme has supported a number of innovative and creative projects to develop technologies but it has been difficult to upgrade them to a commercially viable scale. This is because of a lack of market and lack of support from donors, according to Drew; sometimes external support is needed to create a market.

A report² by GIC Ltd and Beaufort International published in June 2003 explored this problem and made a number of recommendations to DFID. The report cited the following causes:

- The financial risks are considered too high. The reasons for this are threefold: ventures are at an early stage of development, carrying a higher risk of failure; their markets are the poor and/or disabled in developing countries; many ventures lack a credible

business plan.

- 'Business-like' activities that are part of project proposal development seem remote from end-beneficiaries.

- 'Venture philanthropy' — grant-based funding targeting core costs rather than project costs — appears to be an appropriate source of funding but is non-existent in the UK (whose government is funding the programme).

Second, there is a need to share the lessons learned. "So much is 'known' and documented, but not used in practice," Drew says. While much has been achieved in this area — in the form of newsletter production, construction of a website, regional round-tables and so on — more could and should be done.

The third lesson Drew cites is: "if we are tackling poverty we have to tackle disability; we can't continue to neglect it." This is perhaps the most important message to emerge from the first phase, and one that figures strongly in a concept paper³ produced by a team from the Overseas Development Group (ODG), University of East Anglia. This paper, which has informed the second phase of the KaR programme, discusses the links between disability, poverty and technology.

The ODG paper

One of the key points to emerge from the paper is that the main emphasis of the second phase of the programme has moved away from technology and onto disability (as reflected in the change of name). The paper recognises that technology can be "immensely liberating and empowering for disabled people if developed within a framework

which prioritises their real needs as well as their genuine participation at all levels.” However, it needs to be “3A” — appropriate, accessible and amenable — to the needs of disabled people.

The paper places firm emphasis on the connections between poverty and disability, warning: “Poverty, disability and impairment are clearly linked in a deadly embrace.” It describes poverty as a root cause of many forms of impairment, and a major factor in transforming impairment into disability. In an article⁴ based on the paper, published in January 2004, Seddon, Albert and McBride say: “Disability exacerbates poverty, while having impairment makes being poor more gruelling and inexorable.” Poverty can undermine the best-planned development initiatives — and must be seen as central to action on disability.

The ODG paper advocates adopting the social model of disability, which “offers a powerful framework for understanding the complex issues of disability, poverty and technology”, revealing disability as a “cross-cutting social issue”³. Thus the new phase of KaR will be driven by the idea that technology, like disability and poverty, must be seen as a social process. Focusing on the material aspects of technological ‘fixes’ can place too much emphasis on the medical model of disability: the idea that impairment is what is ‘wrong’ with someone, and technology can put it ‘right’ — and that impairment and disability are one and the same. Provided that appropriate

technological solutions empower the users, however, technology is of critical importance to the social-model approach, as it can help break down barriers to social integration.

As the ODG paper underlines, the need for a participatory approach in which responses are led by disabled people and their organisations is central to the social-model approach: “Ideally, the more disabled people are involved in debates [...] in their local or national context, the more any debate [...] can be grounded in the social and political realities.”³

Were the phase one projects sufficiently participatory? KaR adviser and one of the paper’s authors, David Seddon, admits: “My reading of the [first phase] was that it tended to lean towards institutions that looked safe, and institutions with strong northern components. That was partly pragmatic and partly because I don’t think the participatory involvement of disabled people was considered. All this militates against

grassroots organisations getting a look-in, and that is to some extent the case with the six new projects in phase two. I hope we can move towards a more participatory approach.”

A ‘demand-led’ support system is required, say the report authors, in which disabled people and their organisations can work with specialists and other facilitators.

One major problem is that disability remains institutionally and conceptually on the margins of development. “Disability is strangely invisible,” says Seddon, “for reasons which have to do with disabled people being hidden and stigmatised.”

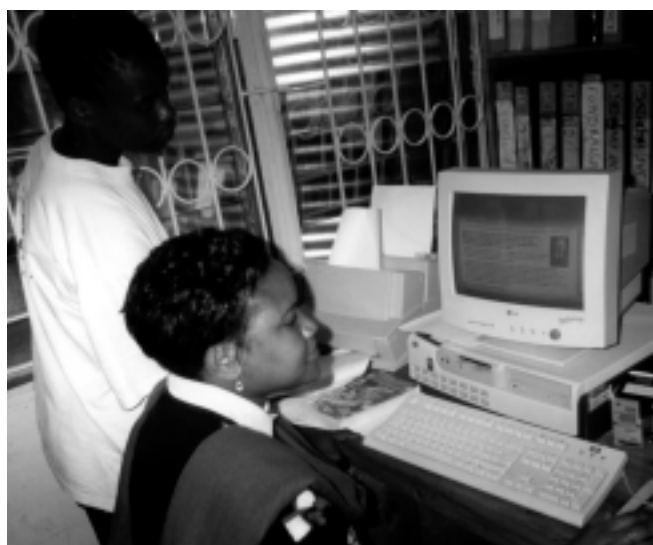
In many developing countries it can be difficult for disabled people to even register as such. Being in a weak and marginalised position, they do not tend to make demands. In the developed world disability has only been recognised as a major development issue in the last few years.

For instance, says Seddon, the UK Government put disability on the agenda of its Social

Exclusion Unit only recently. One of the new projects in the second KaR phase is specifically designed to help DFID develop the focus on disability and development that the report’s authors say is needed.

The Disability Knowledge and Research Programme projects are a further step in this direction, and the programme, it is hoped, will prove itself as an overall learning process.

“Poverty, disability and impairment are clearly linked in a deadly embrace.”
ODG study³



Aiding communication: using TALC’s health information CD-ROM (Photo: TALC)

References

1. *Learning in practice: Lessons from the Disability and Healthcare Technology Knowledge and Research Programme*, Healthlink Worldwide, 2003
2. *Financing large-scale manufacturing of appropriate healthcare technology products for the poor and the disabled in developing countries: A report for the KaR Programme on Disability and Healthcare Technology*, Beaufort International and GIC Ltd, June 2003
3. Albert, W., McBride, R. and Seddon, D. with Cole, K., Cozens, R., Daines, V., Lang, R. and Rao, I. *Perspectives on disability, poverty and technology: A report to Healthlink Worldwide and GIC Ltd*. Overseas Development Group, University of East Anglia, September 2002
4. Seddon, D., Albert, B., McBride, R. 'Perspectives on disability, poverty and technology', *Asia Pacific Disability Rehabilitation Journal* Vol. 15 No. 1, 2004, pp98-107

The 'Learning in Practice' reports and the Overseas Development Group report can be found on the www.disabilitykar.net and www.kar-dht.org websites.

Disability matters in development because...

- There are upwards of 600 million disabled people in the developing world.
- Almost 3.5 billion people are directly affected by having a disabled family member.
- Disabled people are routinely stigmatised and excluded from access to education, transport, cultural and civic activities, healthcare and employment and, because of this, are exposed to pernicious discrimination.
- Disabled people are made dependent and find it difficult or impossible to realise their own potential and contribute to the economic and social life of their society.
- Because it is difficult for disabled people to make a contribution, disability is associated with the most grinding poverty.
- At the same time, poverty remains both a cause and a consequence of disability.
- Reducing poverty is the headline Millennium Development Goal but without tackling disability as a mainstream issue the target of halving poverty by 2015 will never be achieved.
- Disability is above all a critical human rights issue and respecting these rights is a litmus test of any society's commitment to justice, equality and inclusion.
- Genuine social and economic progress can only be achieved by bringing disability into the heart of the development process.
- Leading developing agencies such as the World Bank and USAID are dedicated to putting disability on their development agenda.

“Unless disabled people are brought into the development mainstream it will be impossible to cut poverty in half by 2015.”

James Wolfensohn, President of the World Bank, 2002

Breaking down barriers

A multi-national project team has been working to increase understanding of mobility and access issues that face disabled people in developing countries and to identify ways to address the challenges raised.

Transport policies in developing countries typically fail to address issues of disabled people's access. Lack of access to transport affects disabled people's lives in ways that reinforce links between disability and poverty – for example, by making it difficult for them to get to schools, colleges, health-care centres or employment opportunities.

Over the last three years, the DFID-funded study 'Enhanced accessibility for people with disabilities in urban areas' has been looking at the barriers to accessible transport for disabled people and considering how such obstacles can be overcome.

Phase 1 of the project looked at the mobility needs of disabled people in five case study countries (India, Malawi, Mexico, Mozambique and South Africa), and assessed current practice in Europe, Latin America, Africa and India. It identified three types of barrier to access and mobility: social, psychological and structural (Fig. 1).

Major obstacles that participants in the focus groups identified were high transport costs, lack of awareness among transport staff and the general public of the needs of disabled passengers, and structural barriers in the transport system. (See Reference 1 for further explanation.) The problems and issues associated with each barrier were found to be strikingly similar across the countries in the study and to those in the North.

Phase 2 included the implementation and monitoring of a number of small-scale, low-cost solutions in Malawi, Mozambique, South Africa and India and informing donors of the research activities.

The final output of the research will be a Compendium of Guidelines and Standards, entitled 'Enhancing the mobility of disabled people: guidelines for practitioners'. The drafting of the guidelines — Phase 3 of the project — is partly informed by demonstration projects being undertaken in Mozambique, Malawi, South Africa and India, in which local stakeholders have played a leading role. They are being designed for use by government authorities, advocacy groups, transport

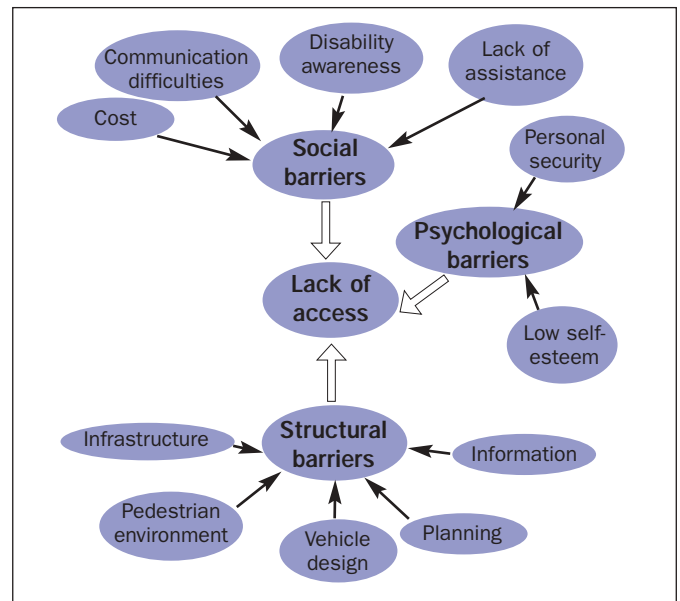


Figure 1. Barriers to accessibility (Source: Reference 1)

operators/planners and donors. They focus on low-cost, incremental approaches that can be easily implemented where financial resources are constrained.

It is anticipated that the guidelines will be available by April 2004 (from TRL or downloadable from www.transport-links.org). They will also be distributed at the Codatu (Romania) and Tranded (Japan) conferences in April and May 2004.

The study is being managed and led by TRL Limited, UK, in collaboration with CSIR Transportek, South Africa; the Central Institute of Road Transport, India; the University of Malawi; Access Exchange International, USA; and the Eduardo Mondlane University, Mozambique. (See www.transport-links.org for more details.)

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CSIR Transportek is managing the Disability KaR programme project 'Low-cost technologies for accessible information on public transport'. See www.disabilitykar.net/projects/publictransport.html for further information. Contact CSIR Transportek on Tel/Fax: +27 12 841 465

References

1. 'Mobility in developing countries', Savill T. et al, *Municipal Engineer* 156, Issue ME2, 2003, ICE.
2. 'Accessibility for people with disabilities', *Transport*, Issue 15, November 2002, DFID.

Sharing wheelchair knowledge

The third All Africa Wheelchair Congress took place in Zambia in August 2003. Christine Cornick of Motivation, UK, reports on the event.

With funding from the DFID Knowledge and Research programme, Motivation team members and more than 20 staff and graduates of the TATCOT Wheelchair Technologists Training Course in Tanzania joined delegates from 14 countries to participate in the third All Africa Wheelchair Congress held in Lusaka, Zambia, in August 2003.

The Congress was officially opened by Khalfan Khalfan,

Chairperson of the Pan Africa Federation of the Disabled (PAFOD), who said that:

“Mobility is one of the most difficult problems of disabled people in Africa and developing countries. Wheelchairs liberate those people with disabilities who need them. Without them, many people with disabilities end up prisoners in their own homes. A wheelchair enables participation in family and community activities, from economic empowerment to advocacy of human rights.”

Congress sessions included wheelchair and hand-tricycle design and production issues, marketing, and wheelchair assessment and prescription. Fatuma

“A wheelchair enables participation in family and community activities, from economic empowerment to advocacy of human rights.”

Khalfan Khalfan, PAFOD

Acan, a wheelchair producer from Uganda and graduate of the TATCOT course, remarked: “The congress has really helped all the organisations involved in wheelchair production in Africa to see how we can collaborate to improve the design and distribution of wheelchairs, and to challenge the importing of old and inappropriate wheelchairs to the continent, which can destroy our local production.”

One of the strongest outcomes of the congress was the recognition of the need for more formal

collaboration and networking between wheelchair builders. This evolved at the congress into the formation of the Pan African Wheelchair Builders Association (PAWBA).

Motivation designer Chris Rushman remarked: “The congress gave us a fantastic

opportunity to share ideas and experiences between our graduates and the other local and international organisations working in wheelchair production in Africa. As part of the KaR programme we will be carrying out new design work over the next year which will draw on the invaluable discussions we had in Zambia.”

As part of the second phase of the KaR Programme, Motivation is developing a new design of hand-propelled tricycle and a wheelchair technology guide, and is evaluating the feasibility of replicating the Wheelchair Technologists Training Course in Central America.

In Africa, the Wheelchair Technologists Training Course has now graduated three intakes of students from Tanzania, Uganda, Zimbabwe, Zambia and Nigeria, the majority of them disabled people who are now establishing wheelchair production networks in their communities.

See www.disabilitykar.net/projects/wheelchairdesign.html and www.motivation.org.uk for more information. Contact Motivation on

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E-mail motivation@motivation.org.uk to receive a copy of their quarterly newsletter, ‘Motif’, specifying whether you would like it by post or e-mail.



The congress delegates

Off to a good start

In November 2003 an inception workshop was held in Norwich (UK), formally marking the start of the Disability Knowledge and Research Programme.

The two-day workshop provided the first formal opportunity for people to meet, exchange ideas and develop a real sense of involvement.

Representatives of the projects, the management team, and the Overseas Development Group (ODG) took part — 14 delegates in total. Their diverse backgrounds encouraged a lively exchange of ideas in an atmosphere that facilitator Ailish Byrne described as “high-energy”.

Networking and the enhancement of mutual understanding were key goals. The focus was placed on communication strategies, effective ways to communicate lessons learned, and the measurement of impact.

The workshop had a participatory style, with an emphasis on active group work; one participant commented: “I like the interactive and fluid approach in which people’s opinions are constantly valued.”

Coherence

KaR Programme Director Roger Drew emphasised the need to form a coherent programme, by combining the different elements — policy, disability equality training, research and the projects themselves.

Drew highlighted the challenges that face all involved, including: the need to illustrate links between disability and poverty and contribute this to the evidence base; to actively inform developments in DFID’s disability-

related policy and practice; and to communicate lessons learned effectively and strategically.

Five of the six funded projects gave presentations (the sixth was unable to attend) and a number of common themes and principles emerged. These included poverty reduction, rights-based approaches, inclusion and empowerment, accessibility enhancement, capacity development, information and knowledge sharing, and skills development. The participants showed a shared social (rather than medical) understanding and approach to disability.

There was also an underlying emphasis on enhancing the livelihoods of poor and disabled people through innovative, practical and transferable low-cost technologies and approaches. The participants showed commitment to working with rather than for people with disabilities.

Communication and impact

Day One focused on communication strategies, led by Andrew Chetley, the programme’s Knowledge and Communications Manager. His message was that communicating is as important as doing.

The groups considered a series of who-why-what-how-when-where questions in relation to their own communication strategies, using the main lessons they wish to communicate as a basis. The implications for the programme’s own communication strategy

were addressed too.

The second day was dedicated to assessing and demonstrating impact. KaR Adviser David Seddon of ODG emphasised the importance of feeding the findings from all the projects into the programme’s research agenda. Don Brown of Information, Training and Development (ITAD) then focused on assessing impact and outcomes using logical frameworks. He stressed the need to demonstrate how the projects will contribute to the reduction of poverty.

One participant said the session had created “a much better understanding of the way things work and how projects fit into the programme”.

Conclusions

The participants seemed to value the opportunity to meet and work collaboratively at an early stage in the programme. One said: “It is useful to know what other projects aim to achieve and to better understand the goals of the programme as a whole.”

The workshop’s participatory approach prompted comments such as: “it was good to interact and link together”, and “swapping ideas was very valuable”.

The participants left Norwich with enthusiasm for the programme, and keen to take part in further collaborative reflection and review events in the future.

Introducing...

Philippa Thomas is the KaR Programme's new Disability Policy Officer. Philippa came into post in January 2004; here she talks about her background and hopes for the programme.

Philippa worked for four years in Cambodia, first as a VSO volunteer teacher-trainer in the provinces and then as a Project Coordinator for education and children with disabilities at the Disability Action Council (DAC).

Her work at the DAC involved advising the Ministry of Education, Youth and Sports on policy towards children with special needs. With the Ministry, local and international NGOs and disabled people's organisations, Philippa was working to establish inclusive education.

Cambodia, she reports, has possibly the highest rates of disability in the world and the DAC is mandated by the government to act as the national coordinating and advisory body on disability. "It was a fascinating organisation to work for and I



believe offers a model for other countries to follow", says Philippa.

Her time in Cambodia informed the dissertation she produced for her recently completed MA in Social Policy and Social Development. Studying at the Institute of Development Policy and

Management at the University of Manchester, she chose to research disability and development, examining the relevance of the DAC in Cambodia within wider debates about disability and poverty.

"I came rather late to the development field", says Philippa. Before going to Cambodia she was a teacher in the UK and Japan and then a professional actress. "In acting you learn the importance of patience allied with persistence and I'm sure this will be invaluable in my new job."

Philippa believes her new position will offer a great opportunity to push disability into the mainstream development process and is looking forward to meeting the challenge.

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Under review

Ziken International is producing, with KaR funding, a set of manuals on medical equipment for the developing world. This article takes a brief look at the review process involved.

The production of Ziken's manuals began in the first phase, KaR-DHT, and is continuing in the Disability KaR phase. The project includes a thorough review process. The aim of this is to ensure that the material reflects conditions in developing countries throughout the world and embraces as many sectors of healthcare as is feasible.

"The process was designed to be as comprehensive as possible," says Rob Parsons of Ziken. The team contracted principal reviewers from nine countries on four continents to comment on all of the guides individually and on the production as a whole. The reviewers included senior staff from government ministries, from NGOs and from the private sector.

Each of the reviewers also found from one to six end-users to comment on specific guides, using a detailed questionnaire issued for each guide. Other international specialists in the field were contracted to comment on specific guides within

their area of expertise.

Each guide thus received what Parsons calls "a comprehensive grilling" from a variety of reviewers. The process was lengthy, but as the final edit and dissemination stages approach, the team is confident that the guides will perform their intended job well. As an unforeseen consequence of the review process, some of the reviewers are already using the guides to inform their work, and are eager to see the finished versions and the guides they have not yet seen.

Parsons concludes: "Bringing together such a wide range of experience and skills has been hard work. But we are about to find out that it was worth it."

**For information on the project's earlier phases see www.disabilitykar.net/lessons/hct8.pdf
Details of Ziken's current KaR-funded work are at www.disabilitykar.net/projects/healthcaretech.html
Contact Ziken on Tel/Fax: +44 (0)117 935 4613.**

Left off the agenda?

An international conference on mainstreaming disability has challenged development agencies to put the needs of disabled people and their organisations firmly on their anti-poverty agenda. How can this be achieved?

London was the location for a two-day conference and associated workshops entitled 'Mainstreaming disability in development: left off the agenda?'. Held in November 2003, it was attended by over 120 people from 20 countries.

The aim of the event, funded by the European Union's Year of People with Disabilities, was to address the very low priority given to the needs of disabled people and their organisations by development agencies in their anti-poverty strategies.

Delegates represented a range of stakeholders – disabled people from the North and

South, service providers, technical support agencies, multi-lateral agencies, academics and donor agencies. The speakers were equally diverse; some of their views are represented on these pages.

A number of key conclusions emerged from the conference:

- Governments must raise the priority of disability on their agenda because it is a rights issue.
- Governments, not benevolent organisations, are the guarantors of disabled people's rights. They have a duty to resource and implement that responsibility.

- The representative voice of disabled people must guide all development policies, programmes and monitoring mechanisms that affect them to ensure mainstreaming.

- Countries cannot afford to keep between 10 and 20% of their populations off their economic, social, cultural and political agenda.

- All development planning criteria, including funding for infrastructure, must address disability issues.

- A society fit for disabled people is the only society fit for all. See www.internationalservice.org.uk website for more information.

VIEWPOINT UK Department for International Development (DFID)

Dr Michael Shultz of DFID said mainstreaming disability is "at the heart" of the department's concern: over the last few years it has moved away from isolated disability-related projects towards integrated support to governments on poverty reduction.

Shultz believes DFID and other agencies can help by supporting disabled people's movements in the South to hold their own governments to account. Recognising the disability agenda in other sectors, e.g. transport, so that disability is given "greater space", is also important.

The audience was invited to monitor the implementation of the Disability, Poverty and Development Issues Paper (see references), which promotes both mainstreaming disability and disability-specific measures. This is part of keeping information flowing – Shultz said the development of DFID's positions over time is often the result of input, advice and lobbying from outside.

VIEWPOINT United Nations

Vittoria Berria, of the UN's Department of Economic and Social Affairs, presented an update on the development of the UN's new Convention of the Rights of Disabled People. The Convention is the first time that civil society – specifically, disabled people's organisations – has been involved alongside UN Member State delegates in the process of drafting text. Berria described it as, "a unique opportunity for building a common agreement."

The Convention's purpose is to raise the visibility of disability, to promote a culture of dialogue and trust, to increase the social inclusion of disabled people, to promote best practice, and to pool scattered knowledge. (See www.dpi.org/en/resources/topics/topics-convention.htm for more information.)

A Working Group met from 5 to 16 January 2004 to draft the text of the convention. There is a virtual forum for public discussion at www.un.org/esa/socdev/enable/rights/.

A word from the delegates

“The role of disabled people is vital. We need to work with many people: donors, community agencies, development agencies etc. to lobby governments [in the South] to include disabled people in their policies.”

Mme Djikiné, West African Fed. of Disabled Persons, Mali

“The conference has been a unique opportunity for people to gather from all over the world ... to exchange [information about] what has been successful in their countries with other countries, which will convince funders to think about the matter as a whole... and make [disability programmes] a priority.”

Amneh Saquer, UNRWA, Syria

VIEWPOINT Southern African Federation of Disabled People (SAFOD)

Alexander Phiri of SAFOD told the conference that responsibility lies with each government, and that disability needs to be on the economic and social agenda.

In Phiri’s view, initiatives such as the UN Decade of Disabled Persons have had little impact on African governments. In reality, “disability issues are still at the bottom of the list of priorities and it is not easy to change this situation without a long-term vision of a new society,” he said.

How important is mainstreaming to SAFOD? According to Phiri, it means creating “a society for us all”, and “the expansion of possibilities, establishment of new partners, mutual support and solidarity.” He called for the red light to be given to development projects that are not universal.

The challenge in Africa, said Phiri, is to harness political will to commit the necessary resources, and to communicate effectively with disabled people.



“Instead of proving that we are 10% of any given population and 20% of the world’s poorest, we must convince society that we are an irreplaceable part of 100%” Alexander Phiri, SAFOD

VIEWPOINT The World Bank

Judy Heumann, the World Bank’s Advisor on Disability and Development, gave a teleconference with the International Disability and Development Consortium (IDDC) and guests based in London that coincided with the Mainstreaming Disability conference. She stressed the need to encourage countries to include disability data in their poverty mapping, as one step in pointing governments towards mainstreaming disability in policies and services. It is important to encourage an integrated, cross-sectoral approach, she said, and to collaborate with country leaders.

The World Bank is funding a number of small research projects; for example, in Uganda, a poverty mapping exercise is incorporating a census on disability, which is assessing the economic issues that disabled people experience.

There was much positive feedback from the teleconference group, many of whom valued it as an opportunity to make new contacts. Delegates echoed Heumann’s call for collaboration. Among these was Mark Raijmakers of the Dutch Coalition on Disability and Development, who also said that some agencies are struggling to embrace inclusion and mainstreaming, which he believes must be changed through education.

Concluding, Heumann stressed the need for an emphasis on education, with support at country level, because local expertise is often limited. She asked for governments to be lobbied to include disability components in budget allocation criteria. She expressed her hopes for the Global Partnership on Disability and Development that she is developing, as an opportunity for funding, and a vehicle for better knowledge and increased visibility for disabled people.

Useful web-based references

(See www.internationalservice.org.uk for list of conference materials)

- VSO Position Paper: *Disability, VSO and development*:

www.vso.org.uk/publications/positionpapers/olddisability.htm

- USAID Policy Paper on Disability: www.usaid.gov/about/disability/DISABPOL.FIN.html

- The World Bank Disability Conference 2002 website: www.worldbank.org/wbi/B-SPAN/sub_disability_conference_2002_index.htm

- ACP-EU Resolution on the Rights of Disabled People and Older People in ACP Countries, November 2001: www.edf-feph.org/apdg/Documents/EN%20EU-ACP%20Resolution%20disability.pdf

For more references, see page 12

Resources

This issue's resources are themed on discussions of disability and poverty. All of the printed resources listed, and more, are available at the Source International Information Support Centre www.asksource.info

Printed resources

- Coleridge, P. *Disability, liberation and development* Oxfam, Oxford, 1993

The book's recurring theme is that disabled people need to participate in the planning and implementing of solutions to their problems if meaningful development for them is to take place. Encourages professionals, policy-makers and disabled people to reflect on their own awareness of the issues.

ISBN: 0 85598 194 6 Price: £9.50

Available from Oxfam, c/o BEBC, PO Box 1496, Parkstone, Dorset BH12 3YDUK. E-mail: oxfam@bebc.co.uk
Website: www.oxfam.org.uk/publications.html

- Department for International Development *Disability, poverty and development* DFID, London, 2000

Assesses the significance of disability as a development issue, its importance in relation to poverty, human rights, and the achievement of development targets. Sets out ways in which development cooperation can help incorporate rights and needs of disabled people into mainstream poverty reduction work.

ISBN: 1 86192 252 3 Available from DFID, 1 Palace Street, London SW1E 5HE, UK E-mail: enquiry@dfid.gov.uk
Full text on website: www.dfid.gov.uk/Pubs/files/disability.pdf

- Elwan, A. *Poverty and disability: a survey of the literature*, World Bank, Geneva, 1999

Background Paper for the World Development Report, World Bank, Washington D.C.

Available from: World Bank, PO. Box 960, Herndon, VA 20172-0960, USA E-mail: books@worldbank.org
Website: <http://publications.worldbank.org/ecommerce/>

- Harris, A. and Enfield, S. *Disability, equality and human rights : a training manual for development and humanitarian organisations*, Oxfam, 2003

Manual based on Oxfam's experience in Kosovo, West Africa and South and East Asia. Suggests practical materials useful for trainers working in geographically isolated areas.

ISBN: 0 85598 485 6 Price: £29.95 Available from: Oxfam, c/o BEBC (as above) or Oxfam 274 Banbury Road, Oxford OX2 7DZ UK Fax: +44 1865 313713 E-mail: publish@oxfam.org.uk
Website: www.oxfam.org.uk/library.htm

- Stone, E. (Ed.) *Disability and development: learning from action and research on disability in the majority world*, The Disability Press, Leeds, 1999

15 original contributions from leading disabled activists, international development planners and practitioners from around the world. Issues covered include empowerment, disabled people's organisations, community-based rehabilitation; inclusive education; and research methodology. ISBN: 0 9528450 3 2 Price: £15.99 plus £1.50 p&p Available from: Disability Press, Disability Research Unit, School of Sociology and Social Policy, University of Leeds, Leeds LS2 9JT, UK

- World Vision *All things being equal: perspectives on disability and development*, World Vision, 2001

This resource calls for action by policy-makers, planners and managers to make development programmes more inclusive. It reports on the barriers put up by communities — as identified by disabled people — that lead to their social exclusion. Available free from: World Vision, 599 Avebury Boulevard,

Milton Keynes MK9 3PG, UK. Tel: +44 1908 841010

Fax: +44 1908 841001 Email: info@worldvision.org.uk

In full at: www.worldvision.org.uk/resources/disabilitypaper.pdf

Web-based resources

www.eenet.org.uk

Website of the Enabling Education Network. Provides access to a broad-based body of expertise and experience in the practice of inclusive education worldwide.

www.chronicpoverty.org

Website of the Chronic Poverty Research Centre, an international partnership of universities, research institutes and NGOs. In the 'Methods Toolbox' is a list of resources on impairment and disability.

Yeo, R. *Chronic poverty and disability* is a useful paper published on this site (Background Paper No. 4, 2001). It reviews of what is known about the incidence, distribution and trends of disability in the developing world, and how these relate to chronic poverty. It presents two case studies (in Uganda and India) where action is being taken to mitigate or reduce chronic poverty among disabled people.

ISBN: 1-904049-03-6

Available in full at www.chronicpoverty.org/pdfs/add.pdf

<http://idpm.man.ac.uk/cprc/Conference/conferencepapers/>

Contents of papers presented at the international conference 'Staying Poor: Chronic Poverty and Development Policy', 7-9 April 2003, Manchester University. Good disability-related resources include: Dyer, S. *The inclusion of disabled people in mainstream micro-finance programmes*; Harris-White, B. *Staying poor: chronic poverty and development policy*; Lwanga-Ntale, C. *Chronic poverty and disability in Uganda*; Yeo, R. *To what extent are disabled people included in international development work? How can the barriers to inclusion be overcome?*

www.adb.org

Website of the Asian Development Bank, a multilateral development finance institution dedicated to reducing poverty in Asia and the Pacific. Type 'disability' into the search box for a large selection of reports, articles and papers.

www.worldbank.org/disability

Includes details of World Bank activities in the disability field, definitions of disability, a directory of disability organisations and web links section.

www.asksource.info/sd-disability.htm

A subject directory containing numerous links to web-based resources on disability and development.

www.healthlink.org.uk/pubs/articles.html

Series of articles on poverty, disability and health, including a look at community approaches to handicap (CAHD) in Bangladesh. Includes further resource lists.

www.iddc.org.uk/dis_dev/mainstreaming/examples.shtml

Includes the Guidance Note on Disability and Development for EU Delegations and Services, March 2003. This note provides guidance to EU delegations and services on how to address disability issues effectively within development cooperation. The note draws on material produced by the European Disability Forum (EDF) and the International Disability and Development Consortium (IDDC).