

Lessons from the **Disability Knowledge and Research Programme**



Lessons from the Disability Knowledge and Research (KaR) Programme

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About this publication

This publication summarises the findings and broader 'lessons learned' from the second phase of the Disability KaR Programme (2003–2005), managed by the Overseas Development Group at the University of East Anglia and Healthlink Worldwide. This phase of the Programme developed a strong focus on mainstreaming disability in development, saw partnerships grow between organisations in developed and developing countries, and saw disabled people taking a lead in research.

Each section of this publication is designed to stand alone or be read in conjunction with the other sections. Research papers and reports produced by or for the Disability KaR Programme are referenced throughout, with a letter and a number (e.g. Ref. B3). These correspond to the references listed in pages 41-42, where you will find the full details. The papers and reports themselves appear on the CD-ROM at the back of this publication.

Acknowledgements

Author: Bill Albert

Editing, design and production: Georgina Kyriacou

Planning: Bernard Trude and Philippa Thomas

Programme Director: Mark Harrison

1 Overview of the Programme

Introduction

The Disability Knowledge and Research Programme (Disability KaR), funded by the UK's Department for International Development (DFID), is one of the most ambitious, wide-ranging and innovative projects on disability and development ever carried out.

In 2000 the Knowledge and Research Programme on Disability and Healthcare Technology was launched and ran until 2003. A budget of £1.2 million was spread over 20 projects.¹ An evaluation report commissioned in 2002 recommended that a second phase focus less on healthcare technology and more on disability as a human rights issue in development.

Although a number of healthcare technology projects continued to be supported, the main emphasis of Disability KaR Phase II² shifted to issues to do with disability, poverty and development. With this change came the more direct involvement of disabled people's organisations (DPOs) in both the UK and the 'South', or developing countries.

This section introduces this 'lessons learned' publication, outlining the main components of the second phase of the Disability KaR Programme and a few of its more significant outputs.

Competition projects

Six projects took place in this phase of the Programme, having bid successfully in a competitive process at the end of the first phase. Their focus was on sustainable new technologies that combat the detrimental effects of disability on the lives of poor people in developing countries.³ The largest single proportion of the Programme budget (38%) was allocated to these projects, which were:

- Low-cost technologies for accessible information on public transport
- Dissemination of a series of practical health care technology management procedure guides
- Development and sharing of wheelchair design knowledge in Africa (see photo)
- Improving access to disability information
- Developing membership recording, tracking and management systems for disability organisations
- Research into health information systems, processes and technologies



One of Motivation's new wheelchair designs, developed with Disability KaR funding

Photo: Motivation

The Policy Project

A Disability Policy Officer was appointed, which was pivotal to the entire Programme. The post provided expert technical policy analysis and support to DFID on disability issues, while ensuring that the other parts of the Programme were responsive to DFID's needs.

The Officer's first task was a detailed mapping of DFID and disability issues, the report of which (Ref. A3) concluded that although there were scattered disability initiatives, disability had not been mainstreamed within the Department. This finding corresponded with that of another report commissioned by the Programme at around the same time: *Disability KaR: assessing connections to DFID's poverty agenda* (Ref. A2). Subsequently the mainstreaming of disability became a central concern of the entire Programme and underpinned the Policy Officer's three country-level research reports on disability and development in Rwanda, Cambodia and India.

A final report by the Policy Officer, *Disability, poverty and the Millennium Development Goals: relevance, challenges and opportunities for DFID* (Ref. A7), brought together all this work as well as findings from other parts of Disability KaR in a comprehensive set of recommendations on the way forward for DFID on disability.

The roundtables

Three roundtable discussion forums, held in Malawi, Cambodia and India, were organised by Healthlink Worldwide and a national DPO or disability organisation in each country. They were preceded and followed by an electronic discussion forum which gave participants the opportunity to develop ideas to discuss at the meetings and keep the discussions alive after the events.

The overall aim was to share learning and research about the relationship between disability and poverty, and mainstreaming disability in development. The meetings provided an opportunity for decision makers to learn from disabled people, DPOs and organisations and institutions working on disability in the South. Participants also came up with practical ideas for taking forward a disability agenda. For example, the Malawi roundtable (Disability, poverty and the Millennium Development Goals) developed guidelines for research as well as a list of priority research topics on disability and development. These then fed directly into the Disability KaR commissioned research projects. In India the roundtable (Mainstreaming disability in development) set in motion an international campaign to get disability included when the Millennium Development Goals are reviewed in September 2005. Finally, the roundtable in Cambodia (Mainstreaming disability in practice: the case of inclusive education) came up with a series of recommendations and action plans for taking forward inclusive education.

Full reports of each roundtable and their outputs can be found at: www.disabilitykar.net/roundtables.rt_intro.html.

Commissioned research

A number of specified research projects were part of the initial contract for the Disability KaR Programme, Phase II. These included substantive studies on

poverty, disability and development and a comparative analysis of disability and gender mainstreaming. There were also briefing notes prepared on the social model of disability and the disability policies of national and international development agencies.

After the UK disability movement became more directly engaged in Disability KaR, and supported by the Programme Advisory Group (PAG), in which disabled people were in the majority, a new research agenda was formulated. This was firmly rooted in the research priorities and modalities of Southern DPOs, as expressed at the Malawi roundtable. It resulted in the production of seven short-term but ambitious projects, all of which were characterised by collaborative working between disabled people in the North and South and the active involvement of Southern DPOs. Reports were delivered on the following subjects (Refs D1-7):

- Research gaps on the topic of disability and development
- Disability policy and legislation
- Mainstreaming disability in development cooperation
- Whether disabled people's voices are being heard in the development process
- The collection and use by disabled people of statistical data
- Inclusive education in Asia and Africa
- Disabled people in conflict and emergency situations

A further four research projects were commissioned by the Policy Officer. The first three of these were carried out by disabled researchers in the South and the fourth involved disabled people in every aspect of the work. These projects (Refs B1-4) looked at:

- Capacity building of disabled people's organisations in Mozambique
- The role and effectiveness of disability legislation in South Africa
- Participation of disabled people in the PRSP/PEAP process in Uganda
- Developing participatory rural appraisal approaches with disabled people in Cambodia

Training course on mainstreaming disability in development

A two-week training course was held at the University of East Anglia, UK, which brought together leaders from the disability movements in Kenya, Fiji, Namibia, Bangladesh, Cameroon, Cambodia, the Netherlands and Malawi, as well as those working for international non-government organisations in Uganda and Bolivia. All aspects of mainstreaming disability were explored, practical tools and guidelines were developed and participants devised action plans to take forward what they had learned.

Communication strategy

Healthlink Worldwide produced a communication strategy for the Programme. The aim was to disseminate information, knowledge and research generated by Disability KaR, as well as to encourage dialogue between the Programme and other national, regional and international programmes, projects, institutions and organisations with an interest in disability. By drawing on the Disability KaR

research findings and the outcomes of the three roundtables, it promoted practical ways of mainstreaming disability and highlighted best practice techniques and strategies.

Conclusion

The Disability KaR newsletter ('DisabilityKaReport'⁵), produced by Healthlink Worldwide, has helped to make an international audience aware of what the Programme was doing, but neither it nor this section can do justice to the richness and variety of the activities carried out under the second phase of Disability KaR.

The face-to-face events, including the roundtables and training events, brought together representatives of DPOs and others not only to share experiences and formulate new ideas but also to put those ideas into action. The Policy Project made a major impact within DFID and helped initiate a more informed and purposeful disability agenda within the Department. Finally, the scope and quality of the research carried out under Disability KaR is truly remarkable, as is the fact that it drew on a novel emancipatory approach, was for the most part carried out by disabled people, and was informed by the basic unifying notion of disability as a fundamental human rights issue.

Notes

1. See www.kar-dht.org/index.html for more information
2. The second phase received £1.4million for two years from September 2003 and was managed by the Overseas Development Group at the University of East Anglia (UEA) and Healthlink Worldwide
3. For project details, see www.disabilitykar.net/projects/projectintro.html
4. Available at www.disabilitykar.net/karreport/karintro.html

Note about references

The reference numbers ('Ref. X') that appear after the names of the papers cited in this section correspond to the references listed in pages 41-42, where you will find the full details. They are all papers and reports produced by or for the Disability KaR Programme. The papers and reports themselves appear on the CD-ROM that comes with this publication.

2 What is disability?

Introduction

It might appear surprising that something apparently as obvious as the meaning of disability should excite controversy. Nonetheless, for many years this question has been the subject of passionate debate. These debates are directly addressed in two Disability KaR projects (cited below) and figure in one way or another throughout all the work done under the Programme. The aim of this section is to outline the findings and to consider why the arguments are important for shaping policies and practices concerned with disability issues in developing countries.

Medical understanding

What most often passes for a 'common sense' understanding of disability is that it is what 'is wrong' with someone. So, 'disabilities' would include blindness, deafness, the various conditions that make it difficult or impossible to walk or to speak, mental illnesses and such things as Down's Syndrome and epilepsy.

Those viewing disability through this medical lens concede that it is unfortunate that many disabled people face social exclusion or poverty but these are seen as the result of the natural functional limitations imposed by their 'disabilities'. Furthermore, as the problem is primarily medical, solutions are generally given over to various caring professionals either to cure, rehabilitate or to protect the individual with a disability. In disability and development these processes usually take place within a charitable context.

Social understanding

'As an individual, I don't have any regret but others underestimate me, they keep reminding me of what I cannot do.' Young man who had polio, training to be a horticulturalist in India (Ref. A7)

The international disability movement (as represented by disabled people's organisations – DPOs) has offered a radical alternative to the medical conception of disability by asserting that people are disadvantaged not by their impairments, but as a result of the limitations imposed on them by attitudinal, social, cultural, economic, and environmental barriers to their participation in society. Rejecting the idea of abnormality, although not the importance of medical intervention or impairment prevention, this 'social model' understanding points to the normality of impairment within any population.

What is disability?

What is not normal, it is argued, is being discriminated against and socially excluded because of having an impairment. This is what is disabling.

Nothing about us without us!

In the Disability KaR paper *The social model of disability, human rights and development* (Ref. C1) it is argued that by seeing impairment as an ordinary part of life, and disability as the result of discrimination and exclusion, the social model underpins efforts to move disability from the medicalised, 'special needs' ghetto and into the mainstream of development policies and practices.

'International Development Targets can only be achieved with the engagement of poor people in the decisions and processes which affect their lives. Human rights are a central part of work to achieve the International Development Targets because they provide a means of empowering all people to make effective decisions about their own lives.'
DFID, *Realising human rights for poor people*, 2001

The social model has also promoted the idea that disabled people should be actors in their own lives, rather than passive recipients of care or charity. This equates almost exactly to current thinking on a human rights-based approach to development, increasingly adopted by government and international development agencies throughout the world. This is explored in the Disability KaR paper, *Disability and a human rights approach to development* (Ref. C4). The Disability KaR Programme exemplifies this approach. When disabled people were brought in to manage the Programme, active engagement with Southern DPOs increased. This resulted in a quantum shift in the quality and depth of understanding of disability. The research clearly reflects this.

By projecting disabled people into a leading role in defining and controlling their lives, the social model also offers a powerful device for the liberation of those who remain the poorest of the poor in all countries, both developed and developing.

The model is so powerful because it illuminates the fact that the roots of poverty and powerlessness do not reside in biology but in society. The former is, for most disabled people, immutable; the latter, through collective action, can be transformed. A human rights approach to development offers both the platform for such societal transformation and a way for disabled people to transform their sense of who they are – from stigmatised objects of care to valued subjects of their own lives. For people who are poor and oppressed this is a key starting point of any meaningful process of social and economic development.

Lessons from gender and development

In the Disability KaR paper *Mainstreaming disability in development: Lessons from gender mainstreaming* (Ref. C3) it is argued that a social-model conception of disability provides a clear parallel with the Gender and Development paradigm in terms of understanding disability as socially constructed, as

resulting from barriers to equal access, as well as from the reality of unequal power relationships across the entire spectrum of development work from policy to practice. As with gender, seeing disability in this way is fundamental to devising effective strategies to tackle the disabling consequences of discrimination and social exclusion.

Trying to capture an illusive concept

Although a social-model conception has helped to change the emphasis of development interventions, uncertainty remains when the term ‘disability’ is used, as it is often applied to ‘impairment’, rather than the process of becoming disabled. This is due partly to the dogged persistence of stereotypical assumptions about disability and partly to the different realms (i.e. social welfare, health, impairment prevention) in which the concept is applied. Also, because disability is socially constructed, it has been difficult to capture in a way that allows simple cross-cultural comparisons. This has made international agreement on meaning virtually impossible and, therefore, has undermined attempts to collect uniform statistical information.

Recently the World Health Organization devised new guidelines (the ICF – International Classification of Functioning, Disability and Health) in an attempt to both overcome some of the aforesaid difficulties, and to harmonise the competing models outlined above.

The ICF takes into account the complicated interrelationships between health conditions, personal aspects and negative environmental (in the broadest sense) factors that, it claims, determine the extent of disablement in any given situation. Although it has been widely seen as a definition, the ICF is more of a framework for making different assessments of disability for different purposes.

The new ICF has been accepted by the World Bank and many other key development organisations and seems set to become the gold standard for understanding and measuring the extent of disability. However, as pointed out in the Disability KaR paper *Is disability really on the development agenda?* (Ref. C2), critics have argued that the ICF represents little more than medical model thinking clothed in social model language, particularly as many professionals continue to pay little attention to environmental impacts and focus instead on impairments.

Nonetheless, it is claimed in the ICF that it ‘... provides an appropriate instrument for the implementation of stated international human rights mandates as well as national legislation.’ It remains to be seen whether it will be used in a way that is helpful in the practical business of designing mainstream development policies and practices that break with traditional medical approaches, challenge accepted power relations and seek to promote human rights by bringing disabled people into the heart of their societies.

The question raised above is tackled in the Disability KaR report on data and statistics (Ref. D5). Researchers working with DPOs in Southern Africa on assessing the living conditions of disabled people have in previous studies attempted to operationalise the terminology in the ICF and apply a disability concept that is founded on activity limitations and restrictions in social participation. Their research under Disability KaR was aimed at exploring the mechanisms needed to ensure how these findings can be used in the best interests of disabled people.

Conclusions

Despite the existence of the ICF, disability continues to be a deeply contested concept. The variety of cultural settings in which it is defined and the different purposes to which such definitions are put would be enough to insure this is true. Added to this is the fact that disability, widely recognised as being the result of systematic discrimination, raises difficult and often uncomfortable personal, social and political questions.

So what is disability?

Disagreements over the answer to this question will continue. However, all the work done under the Disability KaR Programme has adopted, in one form or another, a social model understanding of disability as a starting point. This is not only consistent with what the international disability movement has been arguing for decades, but also with the stated policies of an increasing number of multi- and bi-lateral development agencies.

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3 Disability and poverty

Introduction

For decades the international disability movement has been saying that disability is a cause of poverty, that poverty often leads to disability and that disabled people are among the poorest of the poor in any country. However, it is only recently that a solid platform has been found from which to advance this argument. This has come about through the promotion of the UN's Millennium Development Goals (MDGs), which have prioritised poverty reduction in developing countries, and the establishment by the World Bank and International Monetary Fund of various new aid instruments and procedures, also built ostensibly around reducing poverty.

Unfortunately, those who constructed this platform did so without making disability part of the framework. Disability is not, for example, explicitly mentioned in any of the eight MDGs or the documentation for the new aid instruments or procedures (see Section 3). It has been left to disabled people's organisations (DPOs) and their allies to campaign to get disability onto the development/poverty agenda.

This process is ongoing and has been considerably facilitated by the World Bank, whose former president was an outspoken disability champion. In 2002 a Disability and Development Team was set up at the Bank. Its members have been proactive in supporting research into disability and poverty and finding ways to get DPOs more involved in Poverty Reduction Strategy Papers, one of the main new aid instruments (see section 5). They have also been pushing hard to get the tackling of disability issues recognised as essential for achieving almost all of the MDGs.

'... disabled people are also more likely than other people to live in grinding poverty. More than 1.3 billion people worldwide struggle to exist on less than [US]\$1 a day, and the disabled in their countries live at the bottom of the pile.' James D. Wolfensohn, former president of the World Bank, 2002

The links between poverty and disability figured prominently in the Disability Knowledge and Research Programme. They were a priority issue in all of the many reports by the Disability Policy Officer and the subject of one of the Programme's major research projects.

Disability and poverty: trying to capture illusive concepts

Although the various connections between disability and poverty might appear to be relatively straightforward, the Disability KaR paper *Disability, poverty and the 'new' development agenda* (Ref. C5), has argued that the linkages are in fact deceptively complicated. The hard statistical evidence is also limited and

very sketchy. The report poses some fundamental questions about how the two concepts of disability and poverty are understood and what that understanding means in terms of an analysis of their convoluted interrelationship.

The researchers point out that disability and poverty are highly contested political concepts. Furthermore, because different meanings are used, and there is insufficient care taken to recognise this, commentators are often at cross purposes when debating the issues. For example, disability and impairment are frequently conflated: the latter is confused with how a person with an impairment becomes disabled through complex social processes. As discussed in the Disability KaR paper *Data and statistics on disability in developing countries* (Ref. D5), this definitional problem is compounded by statistical surveys which invariably fail to ‘... detach the issue of disability prevalence from an impairment-based approach to disability.’ Poverty too throws up similar, and in many respects more multifaceted, uncertainties of meaning.

Why are so many disabled people poor? Why are so many poor people disabled?

Bearing in mind the points made above, the Programme’s Policy Officer’s country reports on Rwanda, Cambodia and India (Refs A4-6) provide excellent case studies of the social factors that make it more likely that poor people will contract impairments and why people with impairments are likely to become or remain poor.

Disabled people struggle to find employment in all three countries. Having a physical impairment makes it difficult to work in the agricultural sector, which dominates in all the economies. Vocational training opportunities are

limited, tend to be in urban areas and are not generally linked to gainful employment. Because they are seen as presenting a high risk, disabled people are also usually denied access to micro-credit schemes.

It was found that in Cambodia poor people tend to live near areas that had been mined, are forced to use more risky means of transport, have more dangerous jobs and cannot access health care so that minor illness or injury can become more permanent impairments. Malnutrition, which makes having a whole range of impairments more likely, is also closely associated with being poor.

However, another Disability KaR report from Cambodia, *Developing participatory rural appraisal approaches with disabled people* (Ref. B3), found that ‘...the highest disability (impairment) prevalence rate appears to be in the least isolated village with the best social and economic opportunities, which raised questions about the links between poverty and disability.’ This mirrors the way that the prevalence of impairment is significantly higher in the more economically privileged countries of the North and highlights how complex the poverty-disability-poverty question really is.



Mine field warning, Cambodia

Photo: Philippa Thomas/Healthlink Worldwide

Disability and social exclusion

The prevention of impairment, through mine clearance, inoculation, better health care and/or nutrition, is vital in developing countries, but needs to be clearly distinguished from interventions aimed at combating the social exclusion and denial of human rights that disable people with impairments.

'Rwandan society places little value on disabled people; they are seen as useless and incapable and are stigmatised and discriminated against.'
Country-level research – *Rwanda country report* (Ref. A5)

The reality and extent of the social exclusion of disabled people is brought out starkly in the three country reports mentioned above, as well as the Policy Officer's final report, *Disability, poverty and the Millennium Development Goals* (Ref. A7).

Conclusion

On this and related topics, the Disability KaR Programme's research has provided ample evidence of the interconnected and multi-layered symbiotic relationship between poverty, impairment and disability. This is succinctly summed up in the report *Disability, poverty and the Millennium Development Goals* (Ref. A7):

- Disabled people are typically among the very poorest, they experience poverty more intensely and have fewer opportunities to escape poverty than non-disabled people.
- Disabled people are largely invisible, are ignored and excluded from mainstream development.
- Disability cuts across all societies and groups. The poorest and most marginalised are at the greatest risk of disability. Within the poorest and most marginalised, disabled women, disabled ethnic minorities, disabled members of scheduled castes and tribes, and so on will be the most excluded.
- DFID cannot be said to be working effectively to reduce poverty and tackle social exclusion unless it makes specific efforts to address disability issues.

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4 Disability and the Millennium Development Goals

Introduction

Disability is not mentioned in any of the eight Millennium Development Goals (MDGs), the 18 targets set out to achieve these goals, or the 48 indicators for monitoring their progress. Nonetheless, the former president of the World Bank, James Wolfensohn, has said that ‘Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the chance to achieve a primary education by the same date – goals agreed to by more than 180 world leaders at the United Nations Millennium Summit in September 2000.’ This statement is often reproduced by disabled people’s organisations (DPOs) and their allies when lobbying, but it seems to carry little real weight. Disability continues to be largely ignored as an MDG issue.

With respect to DFID, this lack of attention to disability in relation to the MDGs is brought to light in the Disability KaR paper *Disability KaR: assessing connections to DFID’s poverty agenda* (Ref. A2), and in the Programme Policy Officer’s disability mapping exercise, *DFID and disability* (Ref. A3). The question of disability and the MDGs is also referred to in a number of the Programme’s research reports, was the central focus for the first Disability KaR roundtable in Malawi (see page 2), was a key action point at the second roundtable in India and a major question in the Policy Officer’s final report, *Disability, poverty and the Millennium Development Goals* (Ref. A7).

This section outlines why the MDGs are so important for disability and development, why an explicit disability dimension is vital for achieving the MDGs and how the work carried out under the Disability KaR Programme has helped to highlight both of these points and taken the debate forward into action.

The importance of including disability in the MDGs

The exclusion of disability is grievous because the policies of most multi-lateral and bi-lateral development agencies (except USAID) are geared to a greater or lesser extent, to reaching the MDGs. The lack of explicit reference in the MDGs makes it easy for disability to become either peripheral to or to fall entirely off the policy agenda.

For example, when asked why disability seemed to have such a low profile at DFID, staff pointed to the department’s policy focus on the MDGs and the fact that disability had not been identified as a key concern (reported in Refs A3 and D7). Disability is therefore not mentioned in the two MDG-focused White

Papers which inform policy or the Public Service Agreement which details DFID's aims and objectives.

'In the South Asian context the MDGs look like stars and moon up in the sky. Most of the goals in the past have failed to move beyond mere catchy slogans. Education for All, Health for All, Hunger Free Society are mere slogans. One of the reasons is [that] these goals still need to come from the heart of local policy makers. Are they really committed? Do they see people as valued human beings rather than mere targets and beneficiaries? Absence of political will is the single most important problem...' Indumathi Rao, message on the Disability KaR e-forum

At the Disability KaR roundtable in Malawi the participants made some apparently contradictory discoveries. DPOs were not very knowledgeable about the MDGs and the disabled people they represented were often completely unaware of them. However, by getting together to discuss the issues they soon found out that much of their work, and that of some international non-governmental



Photo: Healthlink Worldwide

At the Malawi roundtable participants examined their knowledge of the Millennium Development Goals

organisations was in fact contributing to the achievement of certain MDGs. Roundtable participants decided that donors and governments must be made aware of exactly why ignoring disabled people would undermine efforts to attain the MDGs and of what was already being done by DPOs and others. This was set out in goal-by-goal detail at the roundtable, and this, together with other Programme findings, is brought together in the Policy Officer's final report (Ref. A7).

Below six MDGs of relevance (out of the total of eight) are briefly discussed with respect to disability issues.

MDG 1 Eradicate extreme poverty and hunger

Disability and poverty are mutually reinforcing and disabled people and their families represent a very substantial proportion of the poor, especially the extremely poor.

MDG 2 Achieve universal primary education

This is the only absolute goal and with 98% of disabled children in developing countries not in school it will be impossible to achieve unless they are explicitly brought into the equation.

MDG 3 Promote gender equality and empower women

Disabled women and girls face a complex and layered experience of

discrimination and disadvantage. The target of eliminating gender inequality in all levels of education by 2015 will not be reached without considering disability.

MDG 4 Reduce child mortality

In the developing world mortality for disabled children under five can be as high as 80%.

MDG 5 Improve maternal health

Disabling impairments associated with pregnancy and childbirth affect up to 20 million women a year.

MDG 6 Combat HIV/AIDS, malaria and other diseases

Disabled people are particularly vulnerable to these diseases, which are also a major cause of disabling impairments.

Conclusions

Even if the MDGs represent little more than another set of empty promises, as many critics have claimed, it is clear that to get a foothold on the international development agenda and into donor policies and practices, disability needs to find its place within them. Furthermore, unless disability is included, the prospects for achieving these goals will be substantially diminished.

Arriving at this conclusion, participants at the second Disability KaR roundtable in India, set in motion an action plan to lobby the United Nations and other agencies to get disability recognised within the MDGs. A petition to that effect has been drawn up and an international campaign is in progress to bring the issue to the attention of the five-year review of the MDGs to be held by the UN in September 2005.

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5 Mainstreaming disability in development

Introduction

Mainstreaming disability into development has been the overarching theme of the Disability KaR Programme. This focus was recommended in the first report commissioned for the Programme (Ref. A2). Subsequently, mainstreaming has been the subject of two research papers, three reports, the main topic for two of the Programme's roundtables (see page 2), as well as the primary focus of the Policy Officer's work, including her three country research reports. This section considers why mainstreaming is of such importance and looks at some of the most significant findings.

What is disability mainstreaming?

The concept of disability mainstreaming is not clearly defined in most writing on the subject. In fact, at the Disability KaR roundtable in India participants could not agree on whether inclusion was the outcome of mainstreaming or whether mainstreaming flowed from inclusion.

However, the definition below, adopted in the Disability KaR paper *Mainstreaming disability in development: lessons from gender mainstreaming* (Ref. C3), while not totally uncontested, can be said to be broadly applicable across the entire range of the Programme's outputs. It is derived from the United Nations Development Programme's (UNDP) definition of gender mainstreaming and in that arena has found broad international consensus.

'Mainstreaming disability into development cooperation is the process of assessing the implications for disabled people of any planned action, including legislation, policies and programmes, in all areas and at all levels. It is a strategy for making disabled people's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres so that disabled people benefit equally and inequality is not perpetuated. The ultimate goal is to achieve disability equality.' (Ref. C3)



The India roundtable debated whether inclusion was the outcome of mainstreaming or vice versa

Photo: Healthink Worldwide

Disability equality, like gender equality, is a vital outcome with respect to disabled people realising their human rights. A human rights approach has, in turn, been identified by many agencies, including DFID, as what is required to combat poverty in the developing world.

The constraints on disability mainstreaming vary considerably depending on how and where implementation is attempted. Work coming out of Disability KaR has focused for example on mainstreaming in education, in government policy and in the policies of bi-lateral and multi-lateral development agencies. The first is looked at in section 7 on education, while the second two are outlined below.

Mainstreaming disability at the level of the state

The mainstreaming of disability in government policy and practice has been the key demand of the international disability movement for decades. It also the central plank in the UN's Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1996). But, as of yet, nowhere in either the North or the South has mainstreaming happened. The Disability KaR country reports on Cambodia, Rwanda and India (Refs A4-6) show that although some slight progress has been made, particularly with respect to education, in all these countries disabled people remain almost totally divorced from the social, economic and political mainstream.

But evidence from the Programme (Ref. D7 and report on India roundtable) shows that the mainstreaming of disability issues by their governments continues to be seen by disabled peoples organisations (DPOs) in India, Bangladesh, Afghanistan, Uganda, Zimbabwe, Zambia and Malawi as the key strategy for achieving equality.

'Mainstreaming is about disabled people participating at all levels of society according to his/her choice without facing any barrier. Disabled people will live with dignity in the society where there would be no obstacle, and walls for inclusion and... will able to establish/enjoy their rights and give their opinions.' DPOs in Bangladesh at workshop on mainstreaming (Research gap analysis report for DFID – Ref D1)

However, even where disability mainstreaming policies have been developed, the results have been disappointing. For example, in the Disability KaR report *The role and effectiveness of disability legislation in South Africa* (Ref. B1), it is shown that the country has perhaps the most comprehensive legislation and policy framework for fully integrating disabled people of any country in the world. Nonetheless, its author says that '...with the exception of a few policies such as the Social Assistance Act, the implementation of these policies has had marginal impact on the lives of a majority of disabled people in South Africa.'

Mainstreaming disability in development cooperation

There has been an impressive catalogue of policy initiatives around disability mainstreaming in development cooperation. The US Agency for International Development (USAID) took the lead in 1996 and was followed a few years later

by DFID and the Nordic development agencies. A casual reading would suggest that disability had finally broken through and was now on the development agenda.

In the Disability KaR paper *Is disability really on the development agenda?* (Ref. C2) it is shown that even the most progressive disability policies have not been implemented. It was this disconnection between promise and results which led to more detailed research presented in the Disability KaR report *Has disability been mainstreamed into development cooperation?* (Ref. D7). This found that of all the many development agencies only USAID was beginning to implement a comprehensive strategy of mainstreaming disability. Elsewhere, for example at the World Bank, disability had become much more prominent, but had yet to make a substantive impact on the Bank's core policies or practices.

At DFID too, despite the impressive issues paper *Disability, poverty and development* (2000), which contained proposals for mainstreaming disability, a mapping report (Ref. A3) by the Disability KaR Policy Officer concluded that although there were some significant disability projects, mainstreaming had not been implemented in the department.

'The challenge of mainstreaming disability should not be underestimated. DFID has not lived up to the expectations that were created with the publication of the Issues paper, but research for this report reveals that there are considerable internal and external opportunities for DFID to move forward on this to once again take the lead among development agencies.'
DFID and disability (Ref. A3)

Conclusions

Mainstreaming, whether in the policies of governments or development agencies, is too often viewed as simply a question of ensuring the inclusion of disabled people. There are similarities here to the debates over the Women in Development (WID) approach which was an attempt to give women a role within existing development initiatives. The problem with the latter was that it did not consider why or how women had been systematically excluded in the first place.

There is a danger of the same thing happening in the process of partially institutionalising disability. Here, de-politicised and technocratic approaches tend to be favoured by bureaucrats and the cutting-edge issues implicit in the UNDP-adapted definition of disability mainstreaming, especially to do with institutional discrimination, unequal power relations and the denial of human rights, are too readily forgotten.

It is understandable that the culture and practices of institutions or states cannot be transformed at a stroke, but the challenge for governments and development agencies is to begin the journey by bringing disabled people into the development tent as equal partners. The work done under the Disability KaR Programme provides ample evidence of why this is needed. It has also offered many examples of how it can be done.

The challenge for DPOs and their allies is to realise that after many years of hard campaigning they have finally got the attention of those in power. Now is

the time to hold that attention and keep up the pressure to get disability mainstreamed into the development agenda in a way that makes a real difference to the lives of disabled people.

Note about references

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6 Disability and the new aid instruments

Introduction

For the last few years Poverty Reduction Strategy Papers (PRSP) together with associated aid instruments have been the main multi-lateral mechanisms for providing debt relief and, therefore, development aid, to the world's poorest countries. They also have a major influence on domestic economic and social policies as well as budgets. Unfortunately, disability issues have, on the whole, been ill served by these new procedures.

How to address this problem and move disability onto this new aid agenda was a primary concern of the first two reports produced under the Disability KaR Programme (Refs A2 and A3). Subsequently, it was identified as a major question by disabled people's organisations (DPOs) meeting at the Disability KaR Malawi roundtable (see page 2). As a result, the Programme commissioned a special report on the participation of DPOs in the PRSP process in Uganda. Other Disability KaR studies looking at disability mainstreaming and gaps in research on disability and development also concerned themselves with this question from an international perspective.

The new aid instruments and their importance for disabled people

Since 1996 the World Bank and IMF have attempted to encourage economic strategies that give consideration to poor people, with a package of aid instruments that offer debt relief through budgetary support for the poorest countries. To be eligible a country needs to prepare a PRSP that sets out the policies it intends to follow in order to reduce poverty and foster economic development.

These papers are supposed to be drawn up through a process of engagement with civil society, as well as foreign donors, to become, in effect, a blueprint for a country's social and economic policies. It is for this reason that DPOs have recognised that unless they are included in the discussions and their views taken seriously, disability will continue to be ignored. Furthermore, because disabled people make up a substantially disproportionate number of the poorest in any country, to be effective, poverty reduction strategies must include a clear disability perspective capable of being monitored.

Disability and PRSPs: the story so far

Most development agencies, including the World Bank, are officially committed to mainstreaming gender in their work. Nonetheless, the Disability KaR paper *Mainstreaming disability in development: lessons from gender mainstreaming* (Ref. C3) reported that like gender, disability has been sidelined in the new aid

modalities. This is not a very hopeful sign for the inclusion of disability in the PRSP process.

The overall evidence to date, presented in Disability KaR's *Research gap analysis report* (Ref. D1), confirms this has been the case. While there has been some improvement since the first round of PRSPs, a World Bank report (2004) characterised the coverage of disability as limited and a '... patchwork of fragmented and uncoordinated interventions.'¹ It was also apparent that most references to disability in PRSPs were about social protection rather than social inclusion.

The DPO representatives at the Disability KaR roundtable in Malawi observed that because of dependence on aid, their countries were obliged to concentrate on PRSPs, but that the DPOs did not have the necessary skills or resources to take part in the civil society consultations that are meant to underpin the process. Also, in Uganda, the one example where DPOs were able to participate, they had to fight other civil society organisations and the government for the privilege. This is all the more disheartening because Uganda has an extremely strong disability movement and, more than anywhere in the world, North or South, disabled people are officially integrated at all levels of the state.

DPOs and the PRSP process in Uganda

The most substantial piece of work on disability and PRSPs was that commissioned by Disability KaR on Uganda, looking at the participation of disabled people in the PRSP/PEAP process (Ref. B2). The commission came in direct response to what was learned at the Malawi roundtable and the request from DPOs to find out more and profit from the Ugandan experience.

The study closely follows how the National Union of Disabled Persons of Uganda (NUDIPU) engaged in the process. It is important to note that the Poverty Eradication Action Plan (PEAP), as the PRSP is called in Uganda, was the third such plan, but the first that had an input from disabled people. NUDIPU, supported by Action on Disability and Development (ADD) and the Danish Council of Organisations of Disabled People (DSI), put together a comprehensive submission, drawing on data relating to disability and poverty as well as consulting widely with DPOs in the country.

Besides limitations imposed by the lack of technical expertise, NUDIPU faced difficulties because of donor and government pressure to complete the PRSP quickly. 'As a result, the PEAP process, in which civil society had been meaningfully involved, became constricted into a six month PRSP process from which they found themselves, to some extent, squeezed out' (Ref. B2). It was also felt that the government was using DPO involvement as a way of legitimising the PRSP process, rather than out of any genuine interest in the rights or needs of disabled people.

The main lessons learned were that DPOs needed to be properly resourced to develop their technical capacity to a much higher level in order to make a real impact on the PRSP process. Also, more time and money were needed to inform and engage disabled people so as to lobby more effectively. Finally, in order to ensure the PRSPs were not simply filled with empty promises, cross-cutting disability indicators and performance benchmarks had to be put in place.

Conclusions

At present, governments in poor countries are desperate for aid and there is no commitment from them or donors to support DPOs or other civil society organisations (CSOs). As a result, PRSPs are in danger of becoming what some critics say they have always been – little more than the traditional exercise of World Bank/IMF structural adjustment hidden behind a façade of national and civil society ownership. Only by CSOs working together to exert pressure on their governments can this be turned around.

Donors also have a role to play in making the democratic processes in PRSPs a reality. Disability KaR's initial mapping of disability initiatives at DFID (Ref. A3) observed that because an increasing proportion of aid was being channelled through the new instruments and these gave less scope for imposing conditions on developing countries, the prospects for mainstreaming disability were correspondingly limited. It was suggested that an example should be set to national governments by including DPOs in DFID's consultation processes and supporting them in building their capacity to represent the disabled constituency. This would encourage the creation of a legitimate space for dialogue and engagement in PRSPs/social programmes, and in turn would help disabled people lobby governments more effectively for their rights. The research carried out under the Disability KaR Programme, particularly research by and with DPOs in Africa, has provided well-grounded evidence to support this proposal and demonstrate in detail what is needed to put it into action.

Note

1. World Bank, Disability and Development Team, *Poverty reduction strategies: their importance for disability*, July 2004

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7 Disability, education and development

Introduction

The Millennium Development Goal (MDG) education target is that by 2015 all children will be able to enjoy a full course of primary schooling. It is the only absolute MDG and without the inclusion of disabled children it will be one that is impossible to reach. The extent of the task is demonstrated by the fact that there are over 150 million disabled children in developing countries, only 2% of whom attend school (UNESCO estimates).

Disability KaR Programme research on this topic has looked at issues to do with bringing disabled children into mainstream education. This was highlighted as a key area of concern in the Disability KaR Policy Officer's mapping report of DFID and disability (Ref. A3) and identified as a major research priority at the first Disability KaR roundtable in Malawi (see page 2). It was also the main theme of the third roundtable in Cambodia. Furthermore, inclusive education is the subject of one of the Disability KaR research reports and figures prominently in a number of the Programme's other commissioned studies.

Before outlining some of the findings of the Disability KaR research and roundtables it is necessary to indicate what inclusive education is and why it is important for disabled people and for a human-rights-based approach to development such as that espoused by DFID.

What is inclusive education and why it is important?

Inclusive education is an approach that seeks to meet the learning and schooling needs of everyone and does not segregate some because they might have different needs or abilities. It is based on the idea that segregated education is almost always unequal education and that schools must change in order to accommodate student diversity. Further, it is argued that this diversity fosters an enriched learning environment for all students.

'What we have accomplished in human rights ... is the complete conceptual switch stating that no child should be forced to adapt to education. The principle requires complete reversal. Education should adapt to the best interests of each child.' Dr Katarina Tomasevski, Special Rapporteur on the Right to Education, United Nations Commission on Human Rights, May 2004

With respect to disability, inclusive education was perhaps the earliest issue recognised internationally as critical within the framework of development cooperation. One reason is that the Education for All initiative, launched in 1990 at the World Conference on Education for All in Jomtien, Thailand, was aimed at a wide range of marginalised groups, not just disabled pupils.

UNESCO has claimed that being included within mainstream education is a basic human right, derived both from the Universal Declaration of Human Rights (1949) and the UN Convention on the Rights of the Child (1989). Being able to access this right is also widely seen as one of the most important gateways through which to escape poverty and exclusion, the all too common lot of so many disabled children and their families. This in turn is why the promotion of inclusive education is so vital for development in general and disabled people in particular.

From being 'special' to being included

Despite the evidence of its success and the high-level international support for inclusive education, the efficacy of this approach as well as the practicality of implementing it continue to be questioned. A wide range of related issues were considered in the Disability KaR paper *A Situation analysis and assessment of education for children with disabilities in Bangladesh, South Asia, East Asia and South Africa* (Ref. D2).

Researchers compared the experiences of special, integrated (in which units of disabled children are on a mainstream site) and inclusive education programmes in four countries. While each system was judged to have experienced many difficulties, overall the findings confirmed what has been observed in other countries: education at special schools was more costly, focused on vocational, rather than academic subjects and tended to isolate disabled children from society and society from disabled children.

Despite the benefits of a more inclusive approach, it was not much in evidence in the four areas. Also, only in South Africa was there a comprehensive policy and action plan for educating disabled children. For example, in Bangladesh the National Education Policy (2000) does not even mention disabled children.

In South Africa, Disability KaR research into the role and effectiveness of disability legislation (Ref. B1) found that while there appeared to be a high proportion of disabled children in mainstream primary education, it was mainly because, 'There just are no other services and so disabled children are on the whole 'dumped' into the mainstream schools whether by their parents or the education system.'

Inclusive education: obstacles and opportunities

The Disability KaR paper cited above (Ref. B1), offers a detailed analysis of the many challenges faced by those wanting to introduce an inclusive education system. These were further highlighted, together with opportunities for inclusive education, at the third roundtable, held in Cambodia.

One of the high points of the Cambodia roundtable was a presentation from three disabled students attending mainstream schools. Participants observed that they had been extremely effective advocates for their rights and that such participation by children in workshops and conferences should be encouraged. Interestingly, all the children wanted to be teachers. In Cambodia disabled people cannot attend teacher training schools.

Sin Srey Neth, a blind Cambodian girl (pictured), explained her experience of mainstream education at the third Disability KaR roundtable. She said that she had initial difficulties. Her own and other parents did not understand the abilities of children with disabilities, and their children could not understand how she could read. Some of her classmates said that if they were disabled they would commit suicide. However, she said that she never gave up and that the children and their parents eventually came to understand clearly about her disability and her abilities.



Photo: Healthink Worldwide

The roundtable identified a host of barriers to inclusive education such as lack of policies, funding and government commitment, and negative cultural beliefs and attitudes. However, they ended their meeting on a positive note with very clear action plans to take the inclusive education agenda forward. Among these were: developing a step-by-step framework of action for implementing inclusive education, suggestions for further research, ways to change negative attitudes in the community and good practice guidelines.

Conclusions

Education is a precious key, for none more so than disabled people in the developing world, the vast majority of whom are denied it as a matter of course. Being effectively barred from education makes it difficult to find work and in so doing perpetuates exclusion and poverty. This is why education figures so prominently on the list of important disability and development research themes of virtually every Southern DPO (see Ref. D1).

DFID's policy is tied to the MDGs. The Department is set to spend £1 billion on education between 2004 and 2008. One unambiguous message from the Disability KaR Programme is that to meet its commitments to achieving the MDGs within its avowed framework of human rights, disability must be robustly mainstreamed within all educational initiatives.

Note about references

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8 Disability research: breaking the mould

Introduction

Disabled people have always been involved in disability research in one way or another, but usually as passive subjects, not as active participants or researchers. Also, much of the research on disability and development has been led either by international non-governmental organisations or by non-disabled academics from the North. Sometimes they have worked with disabled people or disabled people's organisations (DPOs), but the latter have usually been involved in a secondary capacity. The Disability KaR Programme has actively challenged this traditional research paradigm and tried to model a different way of engaging in disability and development research. This it has done by building on existing work on emancipatory research, as well as Participatory Rural Appraisal (PRA) techniques.

This section outlines why this new approach is needed, its key characteristics and how it has been applied in various projects within the Disability KaR Programme. It also highlights two Disability KaR projects in which researching the research process itself was a key objective.

Why a new research model for disability and development?

Many funders are now demanding that disabled people be included as a condition for awarding disability project grants. In most cases what this has meant is that Northern-based organisations with the resources and knowledge to bid for such grants have developed research projects and then searched for Southern DPOs willing to become 'partners'. This downstream involvement can result in tokenism, with the research agenda being pre-set, the unequal power relationship between researcher and researched not being challenged and real control remaining in the hands of the intermediary organisation and/or professionals.

The Disability KaR *Research gap analysis report* (Ref. D1) assessed what kind of research process disabled people in the South preferred. It found that while DPOs were willing to work with outside groups, they wanted to assume a more central, lead role. The following observation from the Zambia Federation of the Disabled (ZAFOD) was fairly typical: 'DPOs should play a leading role in this research process with consultancy services from research institutions.' This is a clear restatement of David Werner's famous dictum about the proper relationship between disabled people and 'professionals', shown in the box below.

'...it is time for non-disabled professionals to recognise the right of disabled persons to self control, and therefore to gracefully step to one side, into a role where they, as professionals, are no longer on top but rather on tap.' David Werner, co-founder of the Projimo Project in Mexico

A novel research framework

The approach adopted by Disability KaR is based on an emancipatory research model. This begins by conceptualising disability in social-model terms as a form of oppression – people with impairments being disabled by a complex web of discrimination and social exclusion. The object of emancipatory research is to understand how this happens and discover ways to challenge it. The key to unlocking this process of transformation lies in the knowledge and life experience of disabled people themselves. This is why they need to take the lead at all stages of the research process.

An excellent example of this approach is provided by the research for the Disability KaR paper *Data and statistics on disability in developing countries* (Ref. D5), as well as the previous work upon which it was based. The latter was originally developed by the Norwegian Federation of Associations of Disabled People (FFO) and Southern Africa Federation of the Disabled (SAFOD), who brought in the Foundation for Scientific and Technical Research (SINTEF) in Norway to facilitate the process. The research that followed involved DPOs and their members at all stages.

'[Disabled people] provide realistic information from society and life experience, are able to find out their own problems, they know better about themselves than others ... [and are well placed] to identify ways to resolve problems.' Disabled participants at Disability KaR workshop of National Grass-root Disabled Federation of Bangladesh, 2004

Research linking disabled people in the North and South

Some of the Disability KaR research projects were identified in a fairly traditional manner as part of the initial contract with DFID. However, once the UK disability movement became more actively involved in the Programme there was a notable shift in emphasis. It began with consultation on research priorities with representatives of the disability movement from Europe, Africa and Asia. This engagement was continued at the Disability KaR Malawi roundtable (see page 2). Participants, largely members of DPOs, formulated a research agenda and principles for how the work should be carried out and these in turn informed the projects which were subsequently commissioned. All were carried out within an emancipatory research framework, directly involved disabled people and were informed by the social model of disability. Furthermore they were implemented either by disabled researchers in the South or as North-South collaborative efforts involving DPOs and disabled researchers.

Disabled people empowering themselves through research – participatory rural appraisal (PRA) in Cambodia

The one project which did not conform strictly to the framework outlined above was *Developing participatory rural appraisal approaches with disabled people* (Ref. B3), undertaken by Disability Development Services Pursat (DDSP), a non-governmental organisation in Pursat province, Cambodia. However, the demand for the research came from the recognition by DDSP that its participatory

approach was not empowering disabled people in community assessment exercises. By bringing disabled people in at all stages of the PRA – planning, implementation, monitoring and evaluation – they were attempting to discover a more emancipatory way of doing research.

The results suggest that the experiment was extremely successful. One important outcome was to increase the self-confidence of the disabled people who took part. There was a corresponding increase in awareness among villagers of the fact that disabled people were capable of playing a meaningful role within the community.

'...villagers could see disabled people playing a coordinating role in the PRAs and they could see that disabled people have capacity. They know that disabled people have the right to participate.' DDSP staff member in Cambodia (Ref. B3)

For the DDSP staff it was a valuable learning experience. They all had worked extensively with disabled people, but this was the first time they had worked with them as colleagues. Doing this had effectively challenged the '...tendency for the staff to see themselves on top and providing for their clients, rather than partnering with them to help them achieve their own goals.' Although this is only a first tentative step in developing and working within a fully emancipatory research framework, it is a crucially important step to take.

Conclusions

There are no magic formulae for doing research. Within Disability KaR an attempt has been made to confront the existing relations of research production and begin to transform them. But this is a beginning and as such can claim only partial success. The inclusion of disabled people is but one potentially transforming element, but if it is the only point conceded then it will mask the fact that little in the research process has really changed. As Mike Oliver (a professor of disability studies) has said, '...it seems to me 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.'¹ Creating this 'different game' remains the central challenge for disability research.

Note

1. Mike Oliver, 'Emancipatory Research: Realistic goal or impossible dream?', in C. Barnes and G. Mercer, *Doing disability research*, The Disability Press, Leeds, 1997

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9 Engaging with disabled people's organisations in development cooperation

Introduction

Rule 18 of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1994) urges states to recognise disabled people at all levels of government. It also says that DPOs should be encouraged and financially supported to do this. More than 10 years on and, with a few exceptions, DPOs throughout the world, but especially in the South, are still having to fight to survive, let alone to have their voices heard by those in power.

Why this is the case and what can be done about it are extremely important questions, for development agencies and governments are increasingly being encouraged from a number of quarters to work more closely with DPOs. This is consistent both with a human rights approach to development that promotes the need for disabled people to speak for themselves, and the new World Bank/IMF aid instruments such as Poverty Reduction Strategy Papers (PRSPs) which call for the active participation of civil society organisations (CSOs) in formulating national plans to tackle poverty.

The challenges facing DPOs in development figure prominently in almost all the work carried out under the Disability KaR Programme, as did recommendations for how these could be overcome. This section offers a selection of the main findings.

Challenges for DPOs

In the Programme research, far and away the most consistently mentioned difficulty for DPOs was funding. This applied both to Northern and Southern DPOs, but was more acute for the latter. It was, for example, highlighted by DPOs at the Disability KaR roundtables in Malawi and India (see page 2) and came up in one form or another in almost every research paper.

This was not simply a question of money, but what the DPOs had to do to obtain it. For example, most relied on tightly-conditional project funding, the targeted nature of which often created problems for sustained organisational development. Also, as state support was virtually non-existent, much of the money that comes from Northern donors is channelled through international non-governmental organisations (INGOs). While Southern DPOs appreciated the assistance, two studies that looked at this issue in some depth uncovered considerable tensions between them and INGOs. For example, the Disability KaR research into capacity building of disabled people's organisations in Mozambique (Ref. B4) found that in that country, 'DPOs are ... angry at what

they see as unequal power with their Northern NGO partners, who raise money from the North in the name of disability but do not discuss more openly and flexibly how those considerable resources should be spent.' These sentiments were repeated in other of the Disability KaR research reports.

Linked to financial insecurity were the problems encountered in developing individual capabilities and organisational capacity. This was brought out in many of the studies, but most comprehensively in the Disability KaR paper *Are disabled people's voices from both South and North being heard in the development process?* (Ref. D3). At the Malawi roundtable participants commented on the problems of capacity but it was also felt that 'As disability activists move up the political ladder they develop a "lukewarm" attitude to disability issues and no longer represent disability issues to the governments they are part of. This results in a further decrease in the capacity of DPOs and people with disabilities to self-represent and lobby/advocate for their rights and disability issues in general.'

The question of the extent to which DPOs were representative of disabled people was brought out in the Disability KaR paper *Disability in conflict and emergency situations: focus on tsunami-affected areas* (Ref. D6). In Sri Lanka it was claimed that DPOs, dominated by urban-based middle-class men, had little knowledge about or contact with poor disabled people in rural areas. Of course, being able to draw in a sufficiently broad-based membership is a problem for many DPOs in both the North and South, but it is also a time-consuming, costly business for which resources are hard to attract.

Resource inequalities also figured centrally in the Disability KaR paper *Promoting inclusion? Disabled people, legislation and public policy* (Ref. D4). The point made by the researchers was that to be able to engage meaningfully in key national and international issues, DPOs needed access to various forms of expertise. However, 'Few DPOs can afford such expertise and, when it is available, it is almost invariably provided, pro bono, by disabled people and our supporters on a part-time basis.' A similar problem was observed in Uganda where the National Union of Disabled Persons of Uganda (NUDIPU) had to struggle in order to participate on equal terms in the consultations over the country's Poverty Reduction Strategy Paper (PRSP) (Ref. B2).

Meeting the challenges

Every DPO faces problems depending on a whole range of factors, many of which are country-specific. However, as demonstrated at the Disability KaR roundtables and in the research reports, money, or rather the lack of it, is the root of problems virtually everywhere. It is, therefore, not surprising that a fairly consistent recommendation is that states heed the Standard Rules and develop '... formal and appropriately resourced partnerships between governmental and DPO actors, especially at the local level' (Ref. D4).

The need to build DPO capacity was another point widely made. In Mozambique, for example, DPOs said that this was necessary to give them 'legs with which to walk, or on which to stand' (Ref. B4). This point was general but also made with respect to particular projects. For example the Disability KaR paper *Data and statistics on disability in developing countries* (Ref. D5) called for '...a grassroot strategy ... for doing disability research in low-income countries. The core of this strategy is DPO control and involvement, a close link between

research and application, and long-term capacity building among DPOs.'

There were also demands for greater unity among DPOs to be achieved through better networking and communication and the development of cross-impairment organisations. A good example of this, given at the Disability KaR India roundtable, was of the Orissa State Disability Network that had been established to work at all administrative levels to lobby on disability issues. The lesson here is that only by working in concert will disabled people have the chance of realising social equality – as has been shown by the disability and other emancipatory movements throughout the world.



The Association of People with Disability (APD), one of India's oldest DPOs, gives high quality vocational training in marketable areas such as horticulture

Photo: Philippa Thomas/Healthlink Worldwide

Conclusion

From a number of different angles the new international aid regime has put a great deal of emphasis on the role of civil society in helping to promote economic growth and reduce poverty. However, all too often it seems to be expected that marginalised groups, be they women, poor people or disabled people, will be able to self-organise spontaneously and take part on equal terms with other stakeholders. This is obviously an unrealistic expectation.

It is understandable that in under such conditions Southern DPOs are having to rely on foreign donors for financial support. But all too often rather than developing the sustainable capacity of the DPOs, it is the capacity of the INGOs that is being strengthened through this relationship. As reported in the Disability KaR study on disabled voices (Ref. D3), 'The Northern NGOs and INGOs tend to use the southern DPOs because at the end, they benefit more from these proposals.' At the same time, even with the best intentions on behalf of INGOs, new forms of dependency for disabled people and their organisations are being created. A number of the reports conclude that what is called for is for donors to consider how to find more direct, efficient, emancipatory methods of helping Southern DPOs to empower themselves.

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10 DFID and disability

Introduction

The second stage of the Disability Knowledge and Research (KaR) Programme, between 2003 and 2005, was designed to consider a wide range of issues concerned with disability and development. Within this was the aim to address the overall research objectives of the UK Department for International Development (DFID). It was also intended to raise the profile of disability within DFID and offer recommendations for the more effective mainstreaming of disability in policy and practice.

The leading edge for generating ideas was the Programme's Disability Policy Officer, who spent most of her time working within DFID. She began by carrying out a detailed mapping of disability work within the department, prepared three in-depth country reports, commissioned four substantial research projects and provided technical support on disability to DFID as a whole. Her work, together with the three roundtables and the many other research projects funded by Disability KaR, have yielded a plethora of practical ideas for how DFID can develop a more robust disability agenda.

This section focuses on a few of the key recommendations directed specifically at DFID. Many of the other suggestions from the Programme's work, particularly those that are broadly applicable to all development agencies, have been outlined in previous sections.

Institutional level

DFID's disability policy and its implementation

In her final report, *Disability, poverty and the Millennium Development Goals* (Ref. A7), the Disability Policy Officer argues that it is vital that addressing disability issues is recognised as essential to achieving the Millennium Development Goals (MDGs), upon which DFID's policy commitments are based. All the Disability KaR reports which deal with this emphasise how important it is that disability is recognised as a cross-cutting (mainstream) question at the highest level. Further, to have any impact this has to be clearly communicated and monitored throughout the department. The critical importance of all these factors was also demonstrated in the comparative study of a number of national development agencies, including DFID, in the Disability KaR paper, *Has disability been mainstreamed into development cooperation?* (Ref. D7).

The appointment of a disability policy officer/advisor

The need to mainstream disability within DFID was the main recommendation of the first report commissioned for the Programme (*Disability KaR: assessing*

connections to DFID's poverty agenda – Ref. A2). A key element in carrying this forward was for a Disability Policy Officer to work full time within the department and a post of Disability Advisor to be established. The latter was also seen as an important lesson to be learned from the experience of gender and development by the authors of the Programme's paper, *Mainstreaming disability in development: lessons from gender mainstreaming* (Ref. C3). This point is supported by Disability KaR having demonstrated the exceptional value for DFID staff of having an in-house source of expert technical advice and support on disability issues.

Disability training and staff diversity

If DFID is going to encourage developing countries to mainstream disability into social and economic interventions then it needs to set an organisational example. This idea underpins the Disability Policy Officer's admonition in her final report that, 'Awareness of disability issues can and should be developed through specific training for DFID staff. However, it is no substitute for the understanding that comes from working with and alongside disabled staff.'

Country level

Supporting local DPOs

With an increasing proportion of aid being provided in ways which limit the ability to impose micro-level conditions, one of the most potent ways for DFID to ensure disability gets included in development is by supporting disabled people's organisations (DPOs). Among other things, this gives disabled people the capacity to lobby for their rights and hold their governments to account. The Disability Policy Officer makes a strong case for this in all her reports. Practical examples of how this plays out are also detailed in the Disability KaR reports, *The role and effectiveness of disability legislation in South Africa* (Ref. B1), *Promoting inclusion? Disabled people, legislation and public policy* (Ref. D4) and *Are disabled people's voices from both South and North being heard in the development process?* (Ref. D3).

Ensuring disability issues are included in all processes relating to new aid instruments

DFID engages in and supports efforts to collect data for such studies as Poverty Social Impact Analyses (PSIAs) which help prepare the ground for aid interventions. It is, therefore, in a position to make sure that disability is explicitly included in such processes.

Besides giving general support to DPOs, the Disability Policy Officer also sees a more specific role for DFID. This role is to include DPOs in consultations on Country Assistant Plans (CAPs) as well as providing assistance so that DPOs can participate effectively as part of civil society in formulating Poverty Reduction Strategy Papers (PRSPs). A case study of this is offered in the Disability KaR report, *Participation of disabled people in the PRSP/PEAP process in Uganda* (Ref. B2).

Building disability into country sector support

The Disability KaR country report on India (Ref. A6) provides best-practice examples of how DFID country offices can make significant progress on getting disability taken into account. Among the successes has been the inclusion of disability indicators in agreements with the government on a major education programme, as well as another initiative on child and reproductive health. The office has also been working with a local DPO to develop an inclusive staff recruitment strategy and make sure that the premises are accessible.

Country offices are where DFID's real business takes place. This is why it is so important that ways are found to spread throughout the organisation the lessons learned in India or other country offices about how to design and implement disability-inclusive practices.

Conclusion

In 2000 DFID published an issues paper entitled *Disability, poverty and development* that set out an ambitious disability mainstreaming agenda for the department. But, as the Disability Policy Officer commented in her report, *DFID and disability* (Ref. A3): '...there is little practical evidence that mainstreaming has taken place and disability has hardly registered at all in the development process.' To be fair to DFID, the Disability KaR paper *Is disability really on the development agenda?* (Ref. C2) concluded that disability was not being mainstreamed by any development agency.

The Disability KaR Programme has helped to move things forward substantially. Its innovative research programme – giving a leading role to DPOs and disabled researchers in both the UK and developing countries, its comprehensive policy work and the willingness of staff to embrace new ideas, have combined to position DFID uniquely among development agencies in mainstreaming disability into development.

Note about references

The reference numbers ('Ref. X') that appear after the names of the papers cited in this section correspond to the references listed in pages 41-42, where you will find the full details. They are all papers and reports produced by or for the Disability KaR Programme. The papers and reports themselves appear on the CD-ROM that comes with this publication.

References

Full text versions of the following references are provided on the CD-ROM at the back of this publication, and on the Disability KaR Programme website: www.disabilitykar.net

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1. Healthlink Worldwide, *Highlights from the Disability KaR roundtables in Malawi, India and Cambodia* (August 2005)

Lessons from the **Disability Knowledge and Research Programme**

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DFID Department for
International
Development

Overseas Development Group
University of East Anglia
Norwich NR4 7TJ
United Kingdom
Tel: +44 (0)1603 592813
www.uea.ac.uk/dev/ODG/index.html

ODG
DEV

Healthlink Worldwide
56-64 Leonard Street
London EC2A 4JX
United Kingdom
Tel: +44 (0)20 7549 0240
www.healthlink.org.uk

healthlink
WORLDWIDE
www.healthlink.org.uk