PERSPECTIVES

ON

DISABILITY

POVERTY & TECHNOLOGY

**A Report to Healthlink Worldwide
and GIC Ltd**

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Executive Summary

1. Introduction and scope of paper

1.1. This Working Paper is **a 'think-piece'** produced by **a team of specialists** (see Appendix 1), engaged by the Overseas Development Group at the University of East Anglia, in response to terms of reference drawn up by **Healthlink Worldwide and GIC Ltd.**, based on a concept note by **DFID**. It concludes with a number of recommendations, to DFID and to the KAR Programme Managers, and with some suggestions for further commissioned action-research.

1.2. The Paper argues that the **concepts of disability, poverty and technology**, are best understood in terms of **dynamic social processes** and sets out an approach to disability and development based on **the social model of disability.**

1.3. It argues that national and international statistics on the prevalence or incidence of physical and/or mental impairment are inadequate. Furthermore, such data offers a partial and often misleading notion of social reality of disability in developing countries. It cannot, therefore, be used to gauge the specific needs of disabled people or as a basis for estimating costs and benefits of any particular programme.

1.4. It argues the need to formulate an **integrated strategy** towards disability and development. It recognises the **value of the KAR Programme,** and recommends that DFID maintain its commitment to funding initiatives in applied or **action-research**.

1.5. It considers the KAR Programme in Disability and Healthcare Technology and its **procedures** for selecting projects for funding, and recommends specifically that disability equality training and robust mechanisms for involving disabled people and their organisations be introduced. It examines the specific **criteria** adopted for judging project concept notes and proposals and makes recommendations regarding the choice and weighting of criteria.

1.6. Finally, it provides a set of **recommendations**, a) for DFID in general, b) for DFID in relation to the KAR Programme, c) for the Programme Managers and d) with respect for further work to be undertaken.

2. Disability, poverty and technology

2.1. Although poverty and disability are often conceived as static and specific 'states of being' and technology as infrastructure or equipment, they are all better understood as the manifest outcomes of dynamic social processes**.**

2.2. Disability is not the same as impairment, and the problems and methods of dealing with impairment prevention and with disability are, therefore, often, although not always, significantly different

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2.3. Disabled people have increasingly challenged the view that disability should be equated with impairment (the medical model of disability), arguing that what disables people are the various social and physical barriers, and negative attitudes, which prevent equal participation in community life. Within this social model, disability is seen as the result of social exclusion and discrimination.

2.4. DFID's statement on Disability, Poverty and Development tends to confuse these two approaches but leans towards the medical model, seeing disability as 'long term impairment, leading to social and economic disadvantages, denial of rights and limited opportunities…'.

2.5. The social model offers a powerful framework for understanding the complex issues of disability, poverty and technology. It reveals disability as a cross-cutting social issue, and the primary policy focus then becomes ***changing the conditions and circumstances in which disabled people are constrained or prevented from full participation as equal citizens – that is, reducing social exclusion.***

2.6. Poverty is increasingly being defined in terms of social disadvantage and social exclusion. The term social exclusion helps us understand the processes which reproduce poverty in the broadest sense – oppression, subordination, exploitation and discrimination

2.7. Poverty is the root cause of many forms of impairment. But being poor is also a major factor in transforming impairment into disability. Disability, , exacerbates poverty, while having an impairment makes being poor more gruelling and inexorable. Poverty, disability and impairment are clearly linked in a deadly embrace.

2.8. Technology is the process of the application of knowledge to find effective solutions to social problems. Technology and its outcomes (buildings, transport systems, assistive equipment) can dramatically affect the environment within which people live and work and may itself significantly increase or decrease the barriers which prevent disabled people from participating fully in social life.

2.10. 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. The provision of appropriate technological solutions in a manner which empowers the users should not be seen as outside or opposed to a social-model approach, but as a critically important element in this approach. For example, for millions of poor disabled people, the lack of low-cost, appropriate mobility aids and assistive equipment is a major barrier to social integration.

3. The social model in practice

3.1. The social model has been the foundation for the disability movement, because it offers a true reflection of disabled people's experience and has proved a powerful lever for anti-discrimination legislation and other policy changes. It provides a protean challenge to the disablist paradigm so often associated with the medical model.

3.2. The needs of disabled people (like disabled people themselves) have all too often been equated with 'special' – outside the 'normal' – and disability has all too often been equated with 'abnormality' and with 'illness'.

3.3. There is a tendency for those concerned about 'disability' to speak and act 'on behalf of' disabled people. Charities and NGOs tend to be run by members of social and political elite groups, who may capture or divert programmes and projects. The need for disabled people and their organisations to be actively involved in defining their own needs and designing their own solutions is central for the social model approach.

3.4. Self-reliance does not necessarily mean standing alone; it does mean being in control of what kind of support is wanted and required, by whom or what, and when. This implies a 'demand-led' support system in which disabled people, together with specialists and others serving as facilitators can begin to work together to make judgements about what might prove to be appropriate and sustainable technologies with respect to disability in specific social contexts.

4. The extent of disability in developing countries

4.1. Very little is known in detail about the nature, extent and severity of disability in developing countries; not much more is known about the prevalence and incidence of impairment. Global statistics on impairment (often confused with disability) are unreliable and based on guesstimates. The figure of 600 million people or 10 per cent of the total population is often cited. The new ICIDH-2, which will attempt to measure impairment and disability, is still being developed and has not yet been adopted formally by WHO.

4.2. Attempts have been made to address the problem. The WHO has compiled figures on Disability Adjusted Life Years (DALYs) by region but the measurement itself is based on essentially arbitrary, negative assumptions about the quality of disabled people's lives.

4.3. The available global and regional data indicate that malnutrition, resulting from material poverty, is possibly the single most common cause of impairment and that many kinds of impairment are the result of specific causes for which there exist relatively straightforward and inexpensive preventive measures. Poverty and poor access to simple remedies are thus key factors in the prevalence and incidence of impairment.

4.4. While, in the developed countries of the North, estimates for the proportion of the population with impairments tend to be between 10 and 15 per cent, in the developing countries of the South, the figures tend to be significantly lower, usually below 6 per cent of the total population. Several factors – premature death of disabled people (mainly infants, female children and women), failure to record disabled people in censuses and surveys, and higher 'thresholds' for the identification of impairment and disability – explain these differences.

4.5. The identification and classification of impairment in a population is not the same as the analysis of the nature, extent and severity of disability in a society. It is the latter which is crucial for the reduction of disability, but is even more difficult. Such a task is best undertaken at the national, sub-national and local level where there is a greater opportunity for the specifics of disability to be recognised and understood and the appropriate forms of intervention (technology or other) to be devised.

5. Cost-benefit analysis: the problems of 'measurement'

5.1. The use of conventional benefit-cost analysis, with its emphasis on economic value is not appropriate in assessing the benefits of interventions designed to address disability issues. Nonetheless, cost-effectiveness must be a consideration in the selection of programmes and projects.

5.2. If interventions (technological or other) are both appropriate and sustainable then they will tend to be cost-effective in the sense that they are likely to be widely adopted by relatively large numbers of disabled people and used over a relatively long period of time.

5.3. Ideally, the more disabled people are involved in debates on assessment and evaluation, in their local or national context, the more any debate about costs and benefits can be grounded in the social and political realities. This is already been recognised as effective in various forms of participatory evaluation, whether it be participatory action-research or participatory learning and action.

5.4. There is a growing recognition that it is effective as well as appropriate to involve people at all stages in the formulation, design, implementation, monitoring and evaluation of policies, programmes and projects. Effective, inter-active participatory techniques for 'needs assessment', project appraisal, implementation, monitoring and evaluation, which include and involve disabled people must become part of the repertoire of all those working in the development field, particularly at the local level.

5.5. Our review of experience with disability projects and examination of specific case studies (see Appendices 3, 4, 5 and 6) suggests that all projects should be firmly rooted in the expressed needs and demands of disabled people.

5.6. In most developing countries, the national level is where government and international (bilateral and multilateral) agencies could begin to work together systematically with local NGOs, organisations of disabled people, researchers and others with relevant skills and expertise, to develop appropriate legislation, policy, programmes and even projects to reduce disability.

6. Disability and development: towards an integrated strategy

6.1. Despite the vast number of poor disabled people in the developing world, disability as an issue does not figure in either of the British government's White Papers on International Development, and is barely mentioned in any of the key documents of the international development agencies over the last decade.

6.2. In 2001, DFID produced a paper on 'Disability, Poverty and Development' in which an attempt was made, for the first time, to focus on disability as a significant development issue, linked to poverty, and to develop a framework for addressing disability as a policy issue.

6.3. The KAR Disability and Healthcare Technology Programme is another sign that DFID is beginning to address disability as an issue for action-research as well as for policy and practice.

7. Proposals for the development of DFID's disability strategy

7.1. While the establishment of the KAR Programme and the production of the strategy paper mentioned above indicate an awareness in DFID of the need to address disability within the context of development policy and practice, there is as yet little evidence of an integrated and coherent approach to the issue. Disability remains institutionally as well as conceptually and practically marginalised, with responsibilities within DFID itself fragmented.

7.2. We believe that DFID should integrate disability within the mainstream of its development policy and practice by adopting a social-model approach to disability and by identifying disability as a major cross-cutting issue. This would imply adopting a twin-track strategy – already advocated in DFID's disability paper and adopted with respect to gender issues

7.3. Mainstreaming disability means that all policies, programmes and projects should include disability as a key issue, and that monitoring and evaluation should track both the involvement and empowerment of disabled people in the design and implementation of policies, programmes and projects and the effect of these policies, programmes and projects on disability.

7.4. We suggest that DFID establish a cross-sectoral, cross-thematic Disability and Development unit – or task force – with a clear mandate to mainstream disability and to focus more attention on it as a specific development issue.

7.5 In order to implement the aforementioned policies it is essential that all DFID staff involved have appropriate, social-model based disability equality training. (See Appendix 2)

7.6. DFID should learn from other bilateral development agencies and INGOs, which have begun in the last few years to raise the profile of disability in their policy and practice. [See Section 7 of the main text of the Working Paper and Appendices 7, 8 and 9 re USAID, NORAD and Save the Children UK].

7.7. In terms of defining strategy, one possibility would be to commission a team to re-draft the paper on Disability, Poverty and Development, to appear as a Strategy Paper in the series Strategies for Achieving the International Development Targets. Another would be to produce more focused papers showing how disability would be integrated into the work of specific units and divisions. DFID should also work through the KAR Programme to define a set of understandings and priorities for the funding of action-research and selection of projects.

7.8. DFID should facilitate a greater degree of decentralisation in terms of policy and practice, given the importance of the specific social context of disability. Each country development strategy or PRSP should include a section on disability and development, as an integral part of their overall vision for the development of the country concerned. Country level staff should receive disability equality training.

7.9. DFID should establish and maintain closer links with NGOs and institutions working in the field of disability action-research and implementation and with Disabled People's Organisations (DPOs). At an international level it should make links with other development agencies (governmental and non-governmental) and with DPOs.

8. The KAR Programme

8.1. The KAR Programme is an exciting and important funding innovation, which supports action-research initiatives which might not otherwise be funded. We recommend that, in line with a higher profile for disability in development, the allocation of funds to support disability studies and projects through this Programme be increased.

8.2. The link in the present Programme between disability and healthcare technology, and the membership of the WHO in the PAG, both risk perpetuating an approach to disability based on the medical model, rather than an approach which sees disability as a cross-cutting issue under the broad heading of poverty and social exclusion. We suggest the eventual establishment of a KAR Programme on Disability; in the meanwhile, the PAG could perhaps be divided to deal with disability and healthcare technology separately.

8.3. DFID, the PMC and Programme Managers of the KAR Programme should be concerned to establish closer links on an on-going basis so that the Programme benefits from the development of DFID's integrated strategy for disability and development and also contributes to it, through the accumulated evaluation of the experience of the projects funded under the programme.

8.4. One possibility might be for the KAR Programme itself to support a programme or project ('Mainstreaming Disability') involving a series of workshops, interviews, training sessions and other modes of interaction between key DFID staff, the KAR programme managers and other invited specialists.

9. Assessing KAR projects: selection and criteria

9.1 The present arrangement, whereby the procedures for assessing and selecting projects are undertaken by institutions external to DFID themselves selected through a bidding process, has many advantages, but it also creates a distance between DFID and the KAR Programme which reduces the possibility of continual fruitful exchange of ideas between DFID staff and the action-researchers associated with the projects.

9.2. The KAR Programme Newsletter is valuable, but probably more is needed to ensure effective dissemination of 'best practice'.

9.3. We feel that the selection process, based almost entirely on written submissions and without site visits, tends to discriminate against local groups which do not have pre-existing links with Northern or well-known institutions.

9.4. We see advantages in a more decentralised process, with more real decision-making power closer to 'the field', albeit with a KAR Programme selection committee overseeing the process. The establishment of regional or national panels of 'locally-based' assessors providing a direct input into the selection process should be considered.

9.5. All of those involved in the selection process should have disability equality training. Representatives from British disabled-peoples' organisations familiar with development issues should be included as selectors along with experienced researchers, capable of judging the feasibility, effectiveness and sustainability of all projects proposed

10. Judging KAR applications

10.1. The 'fast track' selection process led to the funding of six disability and healthcare projects. Three of the six related directly to disability and appear potentially useful. The first round proper took place during 2001 and involved a two-stage process: a concept note and a more detailed proposal. Twelve projects were selected from 50 or so concept notes, five relating to disability. All five appear to be good projects worth supporting, although not all were firmly rooted in the expressed needs and demands of disabled people despite

the guidelines for selection (see Appendix 11) which imply an empowering and inclusive approach to people with disabilities.

10.3 No-where in the percentage-based criteria is there mention of the involvement of disabled people or DPOs in project genesis or in control over the process, and only passing reference to the specific role of disabled people in the process as a whole (see Appendix 12).

10.4. While recognising that effective design and management of projects is a legitimate objective for KAR and DFIDa greater focus on the involvement of disabled people in the design and implementation is equally likely to produce an appropriate and suitable project meeting objectives of sustainability and long-term cost-effectiveness.

10.5. It is important also that project proposals demonstrate experience and expertise in action-research. A criticism made by one of the assessors of the second round applications in September 2002 was that 'many of the proposals, while laudable in some respects, showed no awareness of monitoring and evaluating their own work or, even in the case of DPOs, how they might consult and include disabled people. Good quality qualitative research… is broadly based and consultative, is not done to people but with them'.

11. Conclusions and recommendations

11.1. For DFID as a whole

11.1.1. We recommend that DFID adopt an approach to disability, poverty and technology which recognises that these are all the outcomes of complex and dynamic social processes and clearly distinguishes between impairment and disability.

11.1.2. We recommend that DFID recognise and assert the importance of technology not as a set of things or infrastructures but as a process involving the application of knowledge to produce solutions to problems. We also recommend DFID recognise that access to technologies which reduce barriers to inclusion and participation (not only assistive or specifically 'healthcare' technologies) should be seen as a basic human right.

11.1.3. We recommend that DFID promote a twin-track approach to disability, as has been done with gender. All DFID-supported initiatives or projects should be able to demonstrate that they are truly inclusive of disabled people). Significant, additional funds should be made available to support disability-specific initiatives.

11.1.4. We recommend that DFID should establish a Disability and Development Unit, with its own Disability KAR Programme. Alternatively, it should create a specific task-force or unit with a prime responsibility for

disability, whose activities would cut across all MDGs. Disability, like gender, would be regarded as a specific but cross-cutting issue.

11.1.5. We recommend that DFID ensure that each country development strategy or PRSP include (provision for) a focus on disability.

11.1.6. We recommend that DFID embark on a comprehensive programme of disability equality training for its staff as an urgent priority.

11.1.7. We recommend that DFID recognise that the links between disability, poverty and technology are complex and that more action-research is required in this area.

11.2. For DFID re the KAR DHT Programme

11.2.1 We recommend that the value of the KAR Programme for disability action-research and support for new initiatives be recognised and that increased funding be allocatedto this initiative.

11.2.2 We recommend, however, to DFID and to the PAG, that the disability and the healthcare technology aspects of the present programme be separated in future (specifically for any re-bid management contract). The new Disability KAR Programme should focus on all aspects of disability and not technology only. The future of the HCT component of this programme is beyond the scope of this Working Paper.

11.2.3. We recommend that DFID specify in any new tender for the management of the KAR Programme that it expects to see a more decentralised management process in the next phase of the programme.

11.2.4 We recommend that DFID work with the PMC to establish ways in which the KAR programme can influence DFID's main strategy more explicitly.

11.2.5 We recommend that DFID assess any proposals for management of the KAR Programme in terms of who assesses projects being considered for funding and how they carry out the assessment, placing emphasis on the involvement of local experts, disabled people and their organisations, and on non-written means of assessment, such as site visits.

11.3. For the Programme Managers

11.3.1 The KAR Programme should adopt the approach that disability results from the social barriers created by various processes of social exclusion; and that technology is a process of the application of knowledge to produce solutions to problems.

11.3.2. The Programme should not try to make funding decisions on the basis of statistics relating to the prevalence of impairment, but on the basis of the potential for impact (numbers of beneficiaries, sustainability, potential for replicability and changing policy and practice more widely).

11.3.3.The Programme should establish an appropriate balance between projects selected through competition and commissioned work. We would recommend increasing somewhat the proportion of commissioned work to enable the Programme to 'fill gaps' and ensure coverage of urgently needed action-research, while at the same time allowing initiatives to come from 'below'.

11.3.4.Greater priority should be given to encouraging and funding those projects which clearly have the active involvement of disabled people and their organisations, and can demonstrate, through their presentation of research methodology and project monitoring and evaluation, their capacity to deliver high quality and sustainable action-research.

11.3.5.The programme should make more use of local assessors and site visits. It might be possible to constitute a panel of, say, 10 local assessors from different geographical regions who would be involved in some way at both concept note and proposal stage and who might carry out site visits at Proposal stage.

11.3.6. PMC should ensure that everyone involved in the assessment of concept notes and proposals, including PMC staff, PAG members and local assessors have undergone disability equality training.

11.3.7. The programme should in the short run separate the PAGs for disability and healthcare technology (perhaps meeting in the morning and afternoon respectively). WHO should probably not be a member of the disability PAG and current co-chairs could each chair one of the two new PAGs.

11.3.8. Weightings for assessment should be changed to increase emphasis on the involvement of disabled people and on the methodology (including production of a logical framework and monitoring and evaluation), and to reduce somewhat the emphasis on the team. Involvement of disabled people and their organisations should be a separate category and not simply part of methodology. All project submissions should provide a logical framework.

11.4. Future Research

11.4.1. An urgent priority is to increase knowledge about practice and to identify 'best practice' as regards disability and development, both in other government agencies and in non-government organisations. This should be an action-research project in which wide dissemination of the draft findings on an iterative basis would be in-built. Three 'registers' would be valuable: 1) a register or compilation of statements and policies on disability and

development by international, bilateral and non-government agencies and organisations, 2) an international register of organisations and institutions with a proven capacity to design and implement innovative disability projects (including research institutions, NGOS, DPOS and private sector enterprises), and 3) an international network of technology providers for disability reduction.

11.4.3 This working paper was produced on the basis of relatively limited research. It would be cost-effective to commission a more comprehensive study, which would involve a) a review of the literature (and other sources) relating to disability and development, b) a review and analysis of significant programme or project initiatives (involving research and/or implementation), and c) a listing and discussion of country-by-country experience with respect to disability and development. This would constitute a fairly substantial project and could well be published as a book on 'Disability and Development: national and international initiatives'.

4.11.4.4   The area of disability and older people is becoming a matter of major concern in many developing countries as the demographic structure changes. Projects which related to this issue would be a priority.

11.4.5 There is some evidence to suggest that in developing countries many children with impairments die or are hidden. We need to know much more about such children and their early lives.

Perspectives on
Poverty, Disability, and Technology
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1. Introduction and Scope

1.1.   Introduction

1.1.1. In September 2000 DFID launched their Knowledge and Research (KaR) Programme on Disability and Health Care Technology. It is supported by a number of departments within DFID. These include Infrastructure and Urban Development, Social Development and the Health and Population Unit. "The aim of the project is to support the development and application of healthcare technologies and infrastructure and to minimise the detrimental effects of disability on the lives of poor people in developing countries." [1] In furtherance of this programme the contracted managers, Healthlink Worldwide and GIC Ltd., commissioned a study to explore the interrelationship between disability, poverty and technology.

1.1.2. Initially it was envisaged that the study would result in three working papers, to be written from three different perspectives by an economist, a social development specialist and a disability activist respectively. Healthlink and GIC engaged the Overseas Development Group at the University of East Anglia to undertake the study, under the direction of Professor David Seddon. It was subsequently agreed that a single, comprehensive Working Paper would be produced, drawing on the expertise of a variety of specialists.

1.1.3. This Working Paper is the product of a team of eight people with a wide range of relevant experience and different perspectives on disability issues. The team consisted of a 'core' group of three and an advisory group of five, bringing to bear expertise in economics, technology, social development, gender and disability.[2] The methodology adopted was that of a collaborative enterprise involving debate and discussion between the members of the team, so as to enable different perspectives and arguments to be represented without losing the overall coherence of a collective commitment.

1.2. Scope of the paper

1.2.1. The scope of the study, as suggested by Healthlink Worldwide and GIC Ltd. is to:

"…identify and explore the key issues which affect the interaction between poverty, disability and technology, with a particular focus on providing recommendations for the KAR programme concerning the type of

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[1] DFID, "Exploring the Links between Disability, Technology and Poverty: A Concept". nd.
[2] For cv's of those involved see below, Appendix 1.

technological interventions which might have maximal impact on the lives of poor, disabled people".

1.2.2. Besides being a general "think-piece", it was also envisaged that the study would also come up with a number of specific recommendations about the criteria for selecting and assessing projects, as well as indicating areas where the KAR programme could commission work.

1.2.3. After preliminary work by the team, and a presentation to DFID on June 18th 2002 by two members of the 'core' team, a request was made that comments on the wider issues of disability and development outlined in DFID's paper, **Disability, Poverty and Development** be considered, as well as the more specific issues covered in the original terms of reference. It is an unfortunate fact that 'disability' has, until very recently, been effectively marginalised as a concern for development policy and practice. We acknowledge and applaud DFID's willingness now to engage with the complex social processes which create disability and to develop an appropriate approach and framework for policy interventions.

1.2.4. Although the Working Paper attempts to address all of the major issues raised and to contribute to the development of a framework for a coherent and effective approach to disability embedded within DFID's broad strategy for poverty alleviation and development, it should be emphasised that this is still very much a preliminary "think-piece". We have drawn on our collective knowledge and experience, and have reviewed a good deal of the available literature, but have not been able to carry out the in-depth research, either with respect to secondary material or field work, which many of the issues raised demand.

2. Disability, poverty and technology

2.1. Conceptual clarification

2.1.1. Our first task is a conceptual and definitional task. We consider it an *essential pre-requisite* to a) any analysis of the relationship between poverty, disability and technology, and b) the formulation of any specific recommendations relating to the **disability**, the **alleviation of poverty** or the **application of appropriate technology.**

2.1.2. Disability, poverty and technology are generally understood essentially as *'states of being' - static and specific (tangible, material, measurable) entities*. Disability is often equated with impairment (eg. being blind is to have a "disability"), poverty is defined in terms of levels of income, whether absolute, relative or in relation to a poverty line, and technology is viewed either as hardware and/or techniques. While most commentators will admit that each of these issues has a social dimension, usually it remains just that, a "dimension", a secondary consideration.

2.1.3. We will argue that to understand the way in which disability, poverty and technology are interrelated in practice it is necessary to conceptualise

them as ***the outcomes of dynamic social processes.*** This does not mean that impairment, material deprivation or equipment are unimportant, but only that they have little analytical significance outside defined socio-cultural contexts.

2.1.4. This is particularly important when looking at projects for employing technological solutions to prevent people becoming impaired or poor, or to help alleviate or reduce poverty and the impact of disability.

2.1.5. It is worth stressing that projects to prevent impairment are as vital as those designed to reduce disability, and at times the two approaches can work together, for example in HIV/AIDS programmes. However, the problems and methods of dealing with impairment prevention and with disability reduction are more often significantly different. For example, campaigns to combat major causes of impairment, such as river blindness, polio, lack of clean drinking water, malnutrition or landmines, will generally have a broad public-health remit and demand large-scale co-ordinated action. On the other hand, programmes which address disability would tend to focus more on social barriers to inclusion in specific social contexts and be more effectively controlled by disabled people with or without assistance from partner organisations.

2.1.6. Finally, we want to state clearly that assistive technology, far from being antithetical to a rights-based approach to disability, can be immensely liberating if developed within a framework which prioritises the real needs of disabled people as well as their genuine participation at all levels. In fact, it could be argued that access to a wheelchair is a basic human right for someone who would otherwise be unable to take part in any social activity. After all, many disabled people in the developed world would have far less equality of opportunity if it were not for their ability to take advantage of a wide range of assistive devices from lightweight wheelchairs to text phones to computer-based text readers.

2.1.7. Before elaborating our general approach more fully we need to set out briefly the arguments which inform our understanding of disability, poverty and technology respectively.

2.2. Disability

2.2.1. The popular understanding of disability is that it is what "is wrong" with disabled people - the inadequate physiological or psychological functioning which sets them apart from the norm. This equates disability with impairment, and encourages us to speak of 'people with disabilities'. So, if one were to list 'disabilities' they might include being blind or deaf, being unable to walk or speak, having a mental disorder or a condition such as Downs syndrome or epilepsy. This is a medical view or medical model of disability. While those who adopt this approach may concede that there are unfortunate social consequences which arise from being disabled, the essential nature of the problem is a medical one and solution is, therefore, cure or rehabilitation (a

term that pervades much of the disability literature) so as to restore functioning which is "normal for a human being".[3]

2.2.2. Since the 1980's, disabled people in particular have increasingly challenged this understanding, arguing both that there is enormous human diversity and therefore no-one and everyone is "normal" and also that it is not their physical or mental condition (identified as 'impairments') which disables them but the social and physical barriers preventing equal participation in community life. Disability, according to this formulation, is the result of social discrimination and social exclusion. It is a social issue, which demands a socio-political response.

2.2.3. DFID has recently considered[4] these two perspectives on disability and come up with the following working definition of disability. Disability is "long term impairment *leading to* social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community".

2.2.4. A similar conception of disability appears in DFID's strategy paper, Realising Human Rights For Poor People, where it is rightly noted that, "discrimination is a form of social exclusion and a cause of poverty", but then suggested that "some people may be unable to access the resources made available by growth because of discrimination against their gender, skin colour, age, disability or other identity"[5]. We would argue *on the contrary* that it is discrimination and exclusion which are themselves the disabling agents. As Save the Children UK recognise, it is "the way in which society responds to …impairments which is disabling, responses which include discrimination, negative attitudes and exclusion".[6]

2.2.5. The notion of disability as impairment, present in the DFID paper, is, we would suggest, an inadequate definition on a number of counts. It prioritises the characteristic or condition of the individual[7] by seeing it as 'leading' to various forms of social exclusion, whereas we would argue that it is society which creates the barriers which 'lead' to or create disability (which is, broadly, being deprived of the ability to play an equal part in the life of the

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[3] This is the term used in the World Health Organisation's 1980 International Classification of Impairment, Disability and Handicap (ICIDH). This has been revised subsequently, firstly (in 1997) as ICIDH-2 (International Classification of Impairments, Activities and Participation), and more recently (May 2001) adopted as ICFDH (International Classification of Function, etc.

[4] DFID, Disability, Poverty and Development, 2000, p. 2.

[5] DFID, Realising Human Rights for Poor People, p. 7.

[6] Community Based Rehabilitation: global review and seminar report, Save the Children UK, November 2000, p. 7.

[7] Even the concept of impairment as 'a state of less than normal functioning' is socially constructed, both in the sense that it posits as 'normal' an ideal state ('without impairment') and in the sense that many characteristics 'become' impairments only under specific social conditions – eg dyslexia which constitutes a recognisable impairment only when high levels of literacy and numeracy are socially required, or 'colour blindness' which is relevant only in very particular circumstances. The prevention and mitigation of impairment is an important but also, we would argue, controversial and problematic element in the reduction of disability

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community). The report goes on to say[8] that it has adopted "an integrated approach using best practice in both social and medical terms." But in fact, by doing this it has sacrificed intellectual coherence for the mistaken assumption that a middle position offers a reasonable compromise.

2.2.6. What it does *not* offer is the possibility of effectively addressing those factors which disable people by developing a clear and coherent framework specifying clearly the relationship between disability and impairment; it simply equates the two. The confusion inherent in the DFID approach in this instance is shown by the use throughout the document of the term "people *with* disabilities".[9] In effect, this suggests a medical model understanding of disability clothed in social model language and sentiments.

2.2.7. It should be noted that models are not definitions. They are intellectual constructs whose purpose is to help understand something, usually with the caveat 'everything else being equal'. "A good model can enable us to see something which we do not understand because in the model it can be seen from different viewpoints (not available to us in reality) and it is this multi-dimensioned replica of reality that can trigger insights which we might not otherwise develop."[10]

2.2.8. Although the social model of disability is not without its limitations or its critics, we believe, - and will demonstrate in our analysis - that it offers a powerful framework for understanding the complex issues of poverty, disability and technology. Following from a social-model approach, and in line with the position adopted increasingly by disabled people throughout the world, we view disability as:

> "… a complex system of social restrictions imposed on people with impairments by a highly discriminatory society. Disability, therefore, is a concept distinct from any particular medical condition. It is a social construct that varies across culture and through time, in the same way as, for example, gender, class or caste." [11]

2.2.9. In this sense, ***disability as a policy issue becomes a cross-cutting social one, rather than something primarily associated with health and individual well-being.*** For example, according to a 1995 study,[12] poverty and lack of economic opportunities are identified as major barriers to disabled women's empowerment. Furthermore, as former United Nations Secretary-

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[8] Ibid., p.8.

[9] In many countries, for example the US, "people with disabilities" is used even by those in the disability movement. We do not want to imply that they or their supporters do not understand or put into practice the social model. However, for those outside the movement, most of whom will have a medical-model conception of disability, the use of the term "people with disabilities" can not help but reinforce this conception.

[10] Vic Finklestein, "The Social Model Of Disability Repossessed", Manchester Coalition of Disabled People, December 1, 2001.

[11] Disability Awareness in Action, Overcoming Obstacles to the Integration of Disabled People, Copenhagen, 1995, p.5.

[12] Hershey and Stephens, Leadership Development Strategies for Women with Disabilities: A Cross -Cultural Survey, 1995, p.8

General Javier Perez de Cuellar stated in 1998 (in a report to the UN), "equality of opportunity simply does not exist where a disabled child cannot go to school, where a disabled mother has no health care, where a disabled man cannot get training or a job, or where disabled people cannot move freely on the streets."

2.2.10. It follows from the identification of disability as a social and cultural phenomenon, that **all** interventions should work towards creating " a society where all disabled people can participate fully as equal citizens" [13] The primary focus we advocate is clearly, therefore, on **changing the conditions and circumstances** in which disabled people are constrained or prevented from such participation.

2.2.11. Of course, this does not mean that there are not specific technical interventions or outcomes – accessible buildings, appropriate transport services, wheelchairs, hearing aids, continence devices, etc. - which are essential to allow this participation. David Werner observes,[14]

> "Itis true that social considerations are extremely important, and are still inadequately addressed in most urban 'rehabilitation palaces.' But for millions of poor disabled persons, the lack of low-cost, appropriate mobility aids and assistive equipment is a major barrier to social integration - including schooling, jobs, and self-reliant living."

2.2.12. The point is that these aids and equipment have to be seen, like impairment, as within the range of what is normal social provision, rather than as something 'special' – just as the provision of eye-glasses in most developed countries is seen as part of normal social provision.

2.2.13. What is not normal, or at least should not be normal, is discrimination against and social exclusion of disabled people. ***It is in this context that the provision of appropriate technical solutions in a manner which empowers the users, both with respect to control and the physical ability to take an equal part in society, should not be seen somehow as outside or opposed to a social-model approach, but actually as a critically important element in this approach.***

2.3. Poverty

2.3.1. It is striking that disability does not figure in the international development targets. Furthermore, it is very rarely mentioned in any of the vast number of documents from the international and national development agencies discussing 'poverty'. This, despite the fact that the vast majority of disabled people are poor, and many poor people are disabled.

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[13] Mission Statement of the UK Disability Rights Commission.

[14] David Werner, Nothing About Us, Without Us: developing innovative technologies for, by and with disabled people, p.6.

2.3.2. Poverty has been defined and measured in many ways[15]. After all, deprivation and disadvantage take many forms and have many causes. There seems to be widespread agreement today, however, that in addition to material deprivation, poverty in the developing world should be seen more broadly, in the context of human development and the lack of it.

2.3.3. Increasingly, poverty is understood as the result of social exclusion. Interestingly, this term originated in France, where it specifically referred to disabled people among 'the socially excluded'. The term social exclusion recognises the root causes of material poverty and also helps us to understand the processes, including social and political processes, that lead to poverty in its broader sense. These include oppression, subordination, exploitation and discrimination, which result not only in material poverty, but also give rise to social exclusion, stigma and lack of dignity.[16]

2.3.4. Furthermore, it is increasingly recognised that "vulnerability is a key dimension of poverty. It is a measure of insecurity, defencelessness and the risk of falling into poverty. A broader understanding of poverty must take into account those factors that increase vulnerability. These include the effects of discrimination on the grounds of gender, disability, race, age or ill health, which may make it more difficult for people to earn a living"[17].

2.3.5. Material poverty and poverty in the broader sense, are also associated with, and made more intractable by, lack of access to educational opportunities, health care, adequate nutrition, housing, employment, etc. Poverty is both a cause and a consequence of lack of access to these opportunities; it prevents people from being 'able' to function as full participating members of their community. It is clear from this that, in a powerful sense, *poverty is in itself disabling.*

2.3.6. When physical or mental impairment is added to this 'poverty syndrome', the result is almost always devastating for the individuals concerned, their families and for society. It is clear that in both developed and developing countries disabled people - and among disabled people, women, older people and children - tend to be the among poorest of the poor.[18] *Poverty is also the root cause of many forms of impairment.*

2.3.7. The key point about poverty is that all the elements tend to work in disharmonious concert. This makes it all the more difficult both to define poverty itself and also to un-pick the way so many different factors interact to create it. This is one important reason why developing effective anti-poverty or poverty-alleviation programmes has proved so difficult.

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[15] An excellent overview is provided in UNDP, **Choices for the Poor. Lessons from national poverty strategies** 2001

[9] Ann Elwan, "Poverty and Disability. A Survey of the Literature", a background paper for the World Development Report, World Bank, December 18, 1999.

[17] DFID, Poverty: Bridging the Gap. Guidance Notes. DFID, 2001, p. 24.

[18] Disability Awareness in Action, Overcoming Obstacles …, p.12.

2.3.8. With respect to the relationship between poverty and disability, it becomes particularly difficult to disentangle and deal with when 'impairment' is seen, not only as the defining element of disability, but also as the main focus and causal factor in the poverty and disability equation.

2.3.9. Poverty and disability are clearly linked in a deadly embrace and having an impairment does make being poor more gruelling and more inexorable. ***Not only is poverty itself a major cause of impairment[19], but being poor is a major factor in transforming impairment into disability. Furthermore, it is disability, understood as a socially complex phenomenon, which exacerbates poverty.***

2.4. Technology

2.4.1. Wheelchairs, hearing aids, Braille, artificial limbs, platform lifts, ramps, etc. - technology for disabled people, technological solutions to 'disability'. A view that is simple, straightforward and entirely misleading. Equipment and 'hardware' constitute outputs at an intermediate stage in a social process. They are both the outcomes of technology as the application of knowledge and expertise in a social context; they are also inputs into a process which may, under the right circumstances, change lives for the better.

2.4.2. Motivation, an organisation which develops self-sustaining projects to improve the lives of wheelchair users throughout the world, writes:[20]

> An appropriate wheelchair is a tool with which to access rights, generate income, play a role in community and family life and therefore improve an individual's quality of life. Our extensive experience with a wide range of organisations from government institutions to grass roots disability organisations has proved that receiving a professionally prescribed wheelchair is only the beginning, it forms the vital stepping stone for accessing basic human rights.

2.4.3. While at the intermediate stages such equipment and hardware constitute the most visible feature of technology, at the preliminary stages – identification of problems and possible solutions – and the final stages – assuring continuity and adaptation, and most importantly, facilitating independence, the issues are almost entirely cultural and socio-economic. In this sense ***technology is not a set of things, it is a social process of the application of knowledge to produce solutions to problems.***

2.4.4. It can be helpful to think of technology as particularly relevant to disability in four major domains: 1) the built environment, 2) physical mobility and transport, 3) communications and 4) consumer durables or equipment, for all of these can in very different ways enhance or constitute major barriers to

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[19] UN estimates that more than 40 per cent of impairments are directly attributable to poverty-related factors such as malnutrition and infectious disease. S. Miles, "Strengthening Disability and Development Work", BOND discussion paper, Feb. 1999.
[20] Motivation Charitable Trust, Concept Note for KaR grant, see Appendix 10.

full participation in community activities, particularly – but not only - for people with impairments.

2.4.5. The technology or technologies associated with these domains is/are clearly not confined to 'healthcare technology', but may have very far-reaching implications, both positive and negative, for disabled people as well as for other members of the public.

2.4.6. These domains are not entirely distinct: the built environment, for example, will have relevance for access and physical mobility, may affect communications (visual or audial), and may or may not be suitable for the installation or use of specific items of equipment.

2.4.7. In all of these areas, however, the focus can be either on transforming structures or process which affect large numbers of people (making buildings physically accessible, providing effective public transport systems, improving public systems of communications, etc.) or on producing 'individual-level' technologies (equipment or hardware) which may, nevertheless, be widely replicable, adaptable and therefore applicable. Both are important and both may be successful (in terms of impact and cost-effectiveness) in different ways.

2.4.8. Two major criteria for successful technological innovation are that it is appropriate and sustainable. These are, however, socio-economic, cultural and often political issues, not merely technical issues. For example, importing wheelchairs designed for the US or UK into rural Africa would probably not be either appropriate or sustainable. Motivation have argued that such imports are actually harmful in that, "Large quantities of imported wheelchairs can saturate the market, temporarily diminishing the demand for wheelchairs and destroying smaller wheelchair enterprises to the ultimate disadvantage of the consumer."[21]

2.4.9. Our understanding of technology is, therefore, one in which the social process, and particularly the decision-making process and control, rather than 'the hardware' itself, is the principal focus. This in turn privileges disabled people, their needs and their expertise and prioritises their control of the process over that of 'experts' – whether foreign or local. In the best possible situation technical experts should facilitate and provides specific services, not direct or dictate. In David Werner's phrase, they should be 'on tap, not on top'.[22]

3. The social model in practice

3.1. 'Empowerment', 'human rights', 'equality', 'social inclusion', 'a holistic approach', 'dignity' – these are among the buzz words have become the

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[21] Motivation Charitable Trust, Submission to USAID, Aug. 2002.
[22] David Werner, Nothing About Us Without Us. Developing Innovative Technologies For, By and With Disabled Persons-

common currency in all discussions of disability and development, as indeed more generally in development discourse. However, as is demonstrated in DFID's own document on the subject, this social-model rhetoric can simply obscure what remains, in effect, a view that places impairment centre stage. This positioning marries up too easily with the idea that technical fixes need to be found so that impairment can be overcome, so allowing disabled people to be rehabilitated and then function 'as normal' in the 'normal' world. The social model offers a protean challenge to this disablist paradigm.

3.2. In various forms, the social model has been the foundation stone for the international disability movement[23]. It has been so successful because it offers an accurate reflection of disabled peoples' experience and has proved a powerful lever for such positive changes as anti-discrimination legislation and the independent living movement. It might be thought that because the social model has been counterpoised to the medical-model it would be inimical to questions of health care or assistive technology.

3.3 David Werner suggests that this is the case with respect to disability activists and organisations in the North who have prioritised social issues. He writes, "They already have the essential personal aids they need. So their top priority is the struggle for their social rights. They have tended to project their own priorities onto the poor disabled people of the Third World, whose lack of assistive equipment (braces, wheelchairs, etc.) may be their biggest limitation"[24]

3.4. Although Werner's warning needs to be taken seriously,to see such needs as outside the social model would be to misunderstand both the social model and technology. Everyone needs both health care and various types of assistive technology. As mentioned above, the lack of the latter is particularly disabling in the developing world. Furthermore, "Wellbeing, of which health is a part, is a reflection of general socio-economic conditions".[25] The problem has been that disabled peoples' needs, as disabled people themselves, have been classified as 'special' – outside 'normal' society, and disability has all too often been equated with difference, and particularly with illness. Hence, for example, this KAR Programme links disability with healthcare technology when it could have linked disability to social exclusion, appropriate technology, etc.

3.5. The more disabled people have been brought within the orbit of formal healthcare facilities, the more they and their range of needs as citizens have been redefined as the needs of 'patients' and put in the hands of a whole variety of 'care experts' - occupational therapists, doctors, rehabilitation and social workers, care assistants - and this has been the basis for much of the segregation, discrimination and inequality which characterises disability. This

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[23] Disability "..is the disadvantage pr restriction of activity caused by contemporary social organisation which takes little or no account of people who have impairments and this excludes them from the mainstream of social activities" (Disabled People's International).
[24] Werner, op.cit., p.6.
[25] Barnett & Whiteside, AIDS in the 21st Century: disease and globalization. Palgrave Macmillan, London, 2002, p. 27)

may mean, paradoxically, that there are more disabled people (though not necessarily more people with impairments) in developed than in developing societies where 'care' is more genuinely 'care in the community' and involves less of a hierarchy and fewer systems of control, if – critically - less technology.

3.6. On the other hand, in both developed and developing countries, there is a tendency for those concerned about disability to speak and act 'on behalf of' disabled people. Most charitable NGOs established over the last century or so which are committed to providing assistance to and work for disabled people are very genuine in their concern, but they are different and often very distinct from disabled peoples' organisations (DPOs) in which disabled people speak and act for themselves. The distinction is similar to that in the development literature between NGOs and CBOs (community-based organisations) or 'self-help organisations'.

3.7. The danger of the charitable 'aid' approach is that it is inevitably to some extent 'top-down' and the NGOs concerned tend to be run by social and political elite groups, who may 'capture' and 'divert' programmes and projects in ways not necessarily desired or needed by their 'constituents'. Of course, not all DPOs represent all of their members equally – there is indeed often a hierarchy of impairment even within DPOs (just as there is in the wider society), in which there is a tendency for articulate, middle class men to take the lead and 'capture' the agenda, with their less articulate, female and poorer colleagues being 'spoken for'. It will always be a struggle for the poorest, most socially excluded, even as members of disabled people's groups, to speak and act for themselves.

3.8. While the social model does not in itself say much about what precisely the role of disabled people should be in the provision of services, it does lead first to a recognition that disability is a social phenomenon, in which having an impairment combined with being socially excluded on other grounds also (gender, class, race, etc.) tends to result in marginalisation and discrimination, and second to a people-centred, demand-led, rights-based approach to the assessment of needs and to the provision of services. Both the independent living movement in the US and the social model approach to disability in the UK were developed by disabled people in residential care who had a strong desire for the simple human right of living with autonomy as equal citizens in the community – to be able as far as possible to take control of their own lives and wellbeing.

3.9. The case for disabled people being at the heart of the process of social inclusion can be made firstly as a democratic one – people should be able to have a say in those things which directly affect them[26]. It can also be made in terms of the historical exclusion of disabled people from this process, how this creates the dependency culture and the disabling impact of that. It can also be argued on a purely social efficiency basis - if you ask people what they need, how they want the service delivered and they remain in control the outcomes

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[26] Hence the slogan, 'nothing for us, without us'.

are more likely to be satisfactory for everyone. It can also be argued on the basis of human rights. Significantly, DFID itself has identified three underlying principles, integral to the realisation of all human rights and the achievement of the International Development Targets: participation, inclusion and fulfilling obligation[27].

3.10. Social inclusion does not preclude self-reliance. Self-reliance does not necessarily mean 'standing alone'; it does mean being in control of what kind of support is wanted and required, by whom or what, and when. This implies a 'demand-led' support/service system. And if it is thought – as is often the case with respect to health services – that demand is unlimited and constitutes a bottomless pit into which all of society's resources will drain away, all the evidence available suggests that, on the contrary, a system which genuinely empowers those who use it is more selective, more appropriate to real needs, and more cost-effective.

3.11. It is only when we understand both that disability is socially constructed (not that there are unfortunate social consequences of having an impairment) and that technology is a social process in which the equipment or technique is but a part (an intermediate outcome), that researchers, policy makers and disability activists can begin to work together to make judgements about what might prove to be appropriate and sustainable technology with respect to disability in specific social contexts. Before practical decisions can be taken, however, it is necessary to be able to identify both the needs of disabled people and the extent and nature of disability itself, in specific social contexts.

4. The extent of disability in developing countries

4.1. If researchers, policy makers and disability activists are concerned to assess the extent and significance (severity) of disability in a given population with a view to assessing needs and possible technologies to address those needs, they should be more concerned with the nature and extent of disability than with the measurement of the prevalence and incidence of impairment.

4.2. Although, as we have seen from our discussion of the social model in practice, disability is not the same as impairment, it is clear, nevertheless, that the prevalence and incidence of impairment is widely considered by many to be an important (if not the only) factor in determining the extent and severity of disability.

4.3. Prevalence refers to the absolute number of people with a particular socially identified impairment in a given population at a given time – it is a still photograph of current impairment. The prevalence rate is the percentage of the population which exhibits a particular impairment at a particular time (or averaged over a period of time). Prevalence in itself, however, gives no idea of change, causation, or the social, economic and other dynamics at work,

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[27] DFID, <u>Realising human rights for poor people</u>. October 2000, p. 10.

which might explain the statistics of impairment, let alone the real burden of disability.

4.4. Incidence is the number of new cases which occur over a given time period. The incidence rate is the number of new cases per specified unit of population in a given time period. Prevalence and incidence are the key statistics for tracking the course of an epidemic, such as HIV-AIDS, but they are less useful for making sense of such a complex phenomenon as disability. If we are to understand the significance of HIV-AIDS in terms of disability we need to see it as more than a disease. What is disabling about HIV-AIDS is society's response to those with the infection or the illness – social exclusion.

4.5. The pursuit of prevalence and incidence of impairment at an aggregate level, which is done in effect by abstracting disabled people (as 'categories of impairment') from the socio-economic and cultural contexts in which they live, runs the risk of equating disability with impairment and thereby reinforcing medical-model thinking. This in turn risks undermining attempts to combat the poverty, discrimination and social exclusion that together blight so many disabled peoples' lives.

4.6. Even if such a counting exercise were useful (beyond drawing attention to the very large number of people with impairments across the world), there are no reliable international statistics on either the incidence or prevalence of impairment to validate it. Estimates vary, but according to UN and WHO figures there are about 600 million disabled people throughout the world or about 10 per cent plus of the population. These are, however, only crude estimates,[28] unsuitable for comparative purposes.[29]

4.7. In practice, as Deborah Marks points out, "Many governments have not carried out the necessary research to make an accurate assessment. In any event, what comes to be defined as disability and impairment varies greatly depending on cultures and circumstances within particular countries".[30] The figure of 10 per cent is largely based on data from developed countries where people live longer and where the majority of disabled people are elderly. As Bowron observes. "in Africa many disabled people do not survive long enough to be included in statistics"[31].

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[28] At a recent meeting UN Ad Hoc Committee meeting on a convention on the rights of disabled persons, the Norwegian asked if the statistics division could provide any up-to-date figures regarding the numbers of (disabled people) throughout the world. "Mary Chamie, from the UN statistics division, replied that current figures as provided by states are compilations of non-comparable data. She hoped that future adherence to the International Classification of Functioning, Disability and Health (ICFDH) would make possible the collection of comparable data. The figure of 600 million …worldwide that was referenced in a Rehabilitation International report over a decade ago, stems from the assumption that 10% of the world's population are disabled, and continues to be cited." Reference kindly supplied by Rachel Hurst. A good summary of the inadequacy of the data is provided in Elwin, **op.cit**., pp.5-8
[29] UN, Disability Statistics, nd.
[30] Deborah Marks, Disability: controversial debates and psychosocial perspectives. Routledge, London and New York, 1999, p. 115)
[31] R Bowron (ed). 'Worlds of Difference Supplement', BBC World Service, BBC, London, 1998

4.8. Global figures are of limited value, therefore, except in so far as they can be deployed to underline the scale of the problem worldwide and suggest possible causation. The nature of these statistics means they would be of little use in making overall policy decisions or, on the micro level, decisions about which KAR projects to support. Until the new 'ICIDH-2' (actually, ICFDH, which combines functionality with environmental and other social parameters in measuring impairment and disability) which was adopted in May 2001, is implemented, and this will take many years, we will not have any reliable and internationally comparable data.

4.9. Regional figures, relating to disability and impairment for aggregates of countries, could provide comparative data of interest to regional bodies, and to international bodies concerned with very broad differences in incidence and prevalence as between, say sub-Saharan Africa and Latin America. But again, these data are at the moment of very poor quality and would in any case be of limited value in practical terms, in so far as most data relate to the incidence of impairments (even if referred to as 'disabilities'), rather than to the dynamics and structures of disability.

4.10. Attempts have been made to address this problem. The World Health Organisation has compiled figures on Disability Adjusted Life Years (DALYS) by region[32], but the measurement itself is based on essentially arbitrary, negative assumptions about the quality of disabled peoples' lives and implicitly puts the blame for ill health on disabled people themselves rather than the societies in which they live. Furthermore, such spurious 'scientific' categorisation is not only totally valueless, it is counterproductive when considering the real personal and social impact of impairment in any potentially disabling situation.

4.11. Statistical information at a national or sub-national level about disease and impairment could of course be useful in national disease prevention or health planning exercises. It could also be used as part of an analysis of disability, as it is in a rare example of such work by Susan Erb and Barbara Harriss-White[33].

4.12. Accepting the limitations of the current statistics, UNESCO estimates that globally, mobility impairments are the largest category (32 per cent), followed by severe intellectual impairment (26 per cent), hearing impairment (14 per cent), epilepsy (13 per cent) and, finally, visual impairment (11 per cent).

4.13. As to the immediate causes of impairment at the global level, then it is significant for any analysis of disability and development that malnutrition (associated widely with material poverty) is considered to be the single most common cause (20 per cent), with congenital conditions and diseases (20 per

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[32] WHO Statistical Information System, http://www3.who.int/whosis/menu.cfm
[33] Susan Erb & Barbara Harriss-White (2002), Outcast from Social Welfare: adult disability, incapacity and development in rural south India. Books for Change, A Unit of ActionAid Karnataka Projects.

cent) and non-infectious (mainly respiratory) diseases (20 per cent) also major sets of causes, followed by accident, trauma or war (16 per cent) and 'other' (including infectious diseases and ageing).[34]

4.14. This global picture is constantly changing, however, and specific regional developments – rising or falling material poverty levels, incidence of war and conflict, spread of HIV-AIDS and other infectious disease, for example - may have a very considerable impact at the global level, as well as regionally. Regional statistics often do not include up-to-date information on the effects of rapidly changing national situations (re HIV-AIDS or conflict, for example) on the incidence and prevalence of impairment.

4.15. In developing countries in particular, many impairments appear to be result of factors for which there exist relatively straightforward preventive measures. For example, over 100 million people have impairments as a result of malnutrition, while lack of iodine puts 800 million people at risk of developing learning difficulties. Six million people have leprosy.[35]

4.16. Many, however, are the result of more complex relationships, but still linked to poverty and social disadvantage. Eileen Stillwaggon's comparative study of HIV epidemics in Africa and Latin America, for example, shows the links between poverty, malnutrition, parasitosis and susceptibility to infection in general and to HIV in particular[36]. Directly infectious and contagious diseases remain common (measles, HIV-AIDS) and, although some appear to be on the verge of disappearing (poliomyelitis, smallpox), others are increasing in incidence and prevalence (and are even re-appearing in developed countries (TB). Indirectly infectious diseases (those transmitted via other hosts than human – malaria, bilharzia, river blindness) and parasitic diseases (Guinea worm) remain common in some regions.

4.16. It must be emphasised, yet again, that statistics on the prevalence of disease or other impairment-creating factors do not begin to give us an idea of the scale and significance of disability in the developing world. They do, however, reveal the major causes of impairment to be matters of public concern: poverty, malnutrition and disease.

4.17. In the so-called developed countries of the North, estimates of the proportion of the population that is 'disabled' generally tend to be between 10 and 15 per cent. In the developing countries of the South, the figures tend to be significantly lower, usually between 3 and 6 per cent of the total population[37]. There are several possible reasons for this.

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[34] R Bowron, Op. Cit.

[35] Emma Stone, "Disability and Development in the Majority World", in <u>Disability and Development: Learning from action and research on disability in the majority world,</u> ed. Emma Stone, The Disability Press. Leeds, 1999, p.5.

[36] Elaine Stillwaggon, "HIV transmission in Latin America: comparison with Africa and policy implications", <u>South African Journal of Economics</u>, 68(5): 985-1011.

[37] India and Nepal, for example

4.18. One is that high levels of poverty, malnutrition and disease lead to high morbidity and mortality rates in developing countries, particularly among vulnerable sections of the society, and result in the 'disappearance' from the statistics of a very high proportion of disabled people (especially infants and children, particularly females). Effective prevention of premature deaths through poverty and disease might well result in a higher prevalence of disabled people with impairments caused by other factors.

4.19. Another possible reason is the tendency for respondents to census and survey questionnaires to 'forget' to mention disabled members of the household, for reasons associated with stigma and shame. Also, detailed studies reveal that in developing countries, and particularly among the poor, impairment may not be acknowledged as such, even by those directly affected, unless so severe that it prevents any contribution to household or local community activities. The final reason is that many people who are classified as disabled in the North are not so classified in the South – for example people with mental health problems or learning difficulties are often excluded from disability surveys, as are older people, or those with AIDS.

4.20. Far more important than sets of statistics on the prevalence and incidence of impairment would be a more comprehensive analysis of the causes of different kinds of impairment and of the economic and social processes that underlie the statistics. Even this, however, we must reiterate, is not the same thing as assessing the nature and extent of disability – the social exclusion and disadvantage that results from social, economic and political processes - which cannot be so easily measured and classified.

4.21. Such a task (the analysis of the nature and extent of disability), is most usefully undertaken, we would submit, at the national or sub-national level, where there is a greater opportunity for those involved in research and/or policy-making to engage with the economic, social and cultural characteristics which define and give rise to disability in its various forms and dimensions, and to discuss these with the various organisations of disabled people themselves.

5. Cost-Benefit Analysis: problems of 'measurement'

5.1. If the 'measurement' of disability through figures on the incidence and prevalence of impairments is misguided, there are also difficulties with estimating and assessing the benefits of interventions – programmes and projects – designed to address disability issues.

5.2. The purpose of cost-benefit analysis is to promote and/or identify the most efficient resource allocation when making decisions on project selection. This can be done with respect to an individual project by trying to determine if, over time, the benefits exceed the costs. It can also be carried out to make decisions about competing projects and to choose the one which offers the greatest net benefit.

5.3. The standard criterion for deciding whether a project can be justified in a benefit-cost analysis is net present value - the discounted monetized value of expected net benefits (i.e., benefits minus costs). Having such apparently hard, quantifiable measures upon which either to select projects or judge their success once completed is understandably appealing to funders.

5.4. But the problems both of inadequate statistical data on impairment (as a proxy for 'need') and the need to assign essentially arbitrary values to what are in any case not easily quantifiable variables would make the task of applying the usual formal cost-benefit analysis to the issues we are considering virtually impossible. Of possibly even greater concern, particularly when looking at disability-related projects, is that cost-benefit analysis does not give much weight, if any, to ethical and moral issues. For example, in deciding between supporting a project for those with HIV/AIDS or young people who are blind, a cost-benefits approach might discount heavily the value of the former as against the latter because of life expectancy considerations (using measures such as DALY's).

5.5. Such crude utilitarian concepts of social efficiency are in fact implicit in much of cost-benefit analysis. A system driven or heavily influenced by this amoral principle would risk justifying decisions that were inconsistent with any reasonable sense of fairness or justice.

5.6. Nonetheless, despite practical measurement difficulties and serious questions about the ethical implications, it is clear that given limitations on resources, policies, programmes and projects should all be as cost-effective as possible. Increasing appropriateness and sustainability – both of which depend on proving 'suitable' to the intended beneficiaries and being reproduced or developed over time – increases the number of beneficiaries and the overall impact of the technology concerned.

5.7. In general, maximising positive impact – quality and quantity of benefits and the number of beneficiaries - should be a major objective. If technological innovations are both appropriate and sustainable they will tend to be cost-effective, in the sense that they are likely to be widely adopted by relatively large numbers of disabled people and used over a relatively long period of time.

5.8. But in practice things are more difficult and there are often trade-offs between different groups or kinds of beneficiaries, or between short-term and long-term impact, etc. These are not easily resolved in abstract simply by head-counting or anticipating an estimated number of beneficiaries. Is it better to transform the lives of a relatively few disabled people or improve significantly the lives of a large number?

5.9. Numbers alone do not provide sufficient, and indeed often do not provide the appropriate criteria for judging between alternatives – as those in the health care professions are well aware. If triage is a methodology of the battlefield and hospital emergency room, DALYs might be seen as the 'scientific' quantifiable instruments for making triage decisions. Neither should

be acceptable when considering the impact of any project on the lives of disabled people.

5.10. Ideally, the more disabled people themselves can be involved in these kinds of debates, in their local or national context, the more the debate about costs and benefits can be 'grounded' in the social and political realities. There are well-known participatory methods which could be adapted to facilitate this. These include participatory action research, participatory learning and action and various methods of self-evaluation of projects and beneficiary assessment. (see below 5.14)

5.11. At the same time it has to be recognised that the assessment of needs and effective demand – which helps to identify potential beneficiaries of particular technologies, projects, programmes and policies cannot always be undertaken by disabled people or even by their associations, but must sometimes be undertaken by 'outside' bodies – research or NGOs or government organisations.

5.12. Such organisations tend, in preparing for a needs assessment or assessment of 'demand', to wish, understandably, to determine the nature and size of the population concerned, rather than addressing the issue of what, in this particular social context, creates disability and for whom. This 'cart-before-the horse' approach often leads to an initial process of classifying and categorising the proposed beneficiaries. If an anti-poverty programme is involved, then often it seems important to determine 'who are the poor'; or even 'who are the poorest of the poor', even before 'how is poverty created and reproduced'?; if a project is concerned to reduce disability, then 'who are the disabled people' often takes precedence over 'how are they disabled'.

5.13. Thus, all too often, the simpler measurement exercises precede the more complex, but vital, analytical work. Furthermore, the issues (e.g. what creates disability and form whom?) are often not taken to the communities and the groups concerned for discussion and debate before establishing the priorities, parameters and population-to-be-served of the programme or project envisaged.

5.14. There is now, at least in the case of anti-poverty or poverty-alleviation programmes and projects, a growing preparedness to undertake 'participatory needs assessments', 'participatory wealth ranking' and other forms of 'participatory appraisal' (even if sometimes this is rapidly done, as in PRA) before design and intervention. It is rare, however, for any 'participatory disability assessment' to be undertaken; it is more usual for an externally-imposed classification or ranking to be applied.[38] Effective inter-active participatory techniques for 'needs assessment' must be developed, if the real needs and desires of disabled people are to figure in the design of projects and programmes.

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[38] Increasingly the value of participatory approaches are being recognised in disability work. Cf Peter Coleridge, "Disability and Culture", (eds) Maya Thomas & M. J. Thomas, Selected Readings in CBR, series 1, CBR in Transition.

5.15. When disability is concerned, at the present, there is a tendency to first classify 'people with disabilities' rather to analyse, together with those most directly concerned, the structures or processes which disable, and to equate 'people with disabilities' with 'impairments'. Consequently, one of the first exercises, in practice, all too often is to 'count disabled people' – in fact, to identify the prevalence of different 'impairment categories' - as if this will help understand the factors which create disability in a local community or larger population and set about dealing with these factors. Even if this approach was not problematic in itself (which it is, as we have indicated), the existing statistics are not generally sufficiently reliable to permit it to be done with any degree of confidence.

5.16. Even at the national level, particularly in cases where the total population concerned is large – as in, for example, India, the capacity of government or even major development agencies to undertake the necessary research, let alone to devise and develop an appropriate comprehensive approach and strategy for the investigation and reduction of disability, drawing on the expertise of those with relevant skills and expertise would appear to be limited at the present time.

5.17. It has been observed, with respect to the Poverty Reduction Strategy Papers (PRSPs) now being developed for many countries, that "even full PRSPs have significant deficiencies in their poverty profiles, including lack of specificity about key categories of poor people, and lack of explicit linkage between the means and processes of identifying the poor, and specific dimensions of anti-poverty strategies"[39] . If this is the case with respect to 'poverty', which has been the focus of attention now for many years for development researchers, policy makers and practitioners, then for 'disability' – which we have argued is equally complex – but which is only now beginning to emerge as an issue for concern within development studies and development policy, then we are perhaps a far-cry from comprehensive statistics relating to disabled people.

5.18. Most useful, probably, at this level – and at this stage - would be the development of an overall conceptual approach and general strategy – perhaps in the form of Disability Reduction Strategy Papers, perhaps within the PRSPs, the establishment of an appropriate legal framework for the reduction of discrimination against disabled people, and appropriate guidelines and possibly provision for disability equality training for selected lower-level authorities and institutions working with disability issues.

5.19. In smaller developing countries, however, the national level might well be the most appropriate level at which government and international (bilateral and multilateral) agencies could begin to work together systematically with

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[39] Neil Thin, Mary Underwood and Jim Gilling, Sub-Saharan Africa's Poverty Reduction Strategy Papers from Social Policy and Sustainable Livelihood's Perspective: a report for DFID. Oxford Policy Management Group, Oxford, 2001, p. 4. Cited in Alan Whaites (ed) Masters of their own Development? PRSPs and the prospects for the poor. World Vision, California, 2002, p.20.

local development NGOs, organisations of disabled people, researchers and other with the relevant skills and expertise, to develop appropriate policy, programmes and even projects.

5.20. It is at this level (the national level), we would argue, that it becomes most effective to make decisions about the allocation of resources to programmes and projects, whether government, non-government or 'other', and about the relative 'costs' and 'benefits'. This, we suggest, has implications for DFID's strategy, and for the approach of the KAR Programme to the selection of projects for funding and support.

6. Disability and Development: towards an integrated strategy

6.1. Just as disability has traditionally been hived off to a whole set of supposed 'experts' — so disability issues in development seem to be seen as outside the mainstream of development theory, policy and practice. How else does one explain the fact that although the majority of disabled people in both the North and South are also poor, and in most cases the poorest of the poor, in neither of the British government's recent white papers on international development[40], both of which headline the elimination of poverty as the key policy goal, is there a single mention of disability? In the DFID strategy document, Halving World Poverty by 2015, the only mention of disability is in the context of the consequences of war[41]

6.2. Of course, the British government is not alone in this omission. Nor is it a recent omission. Influential typologies of vulnerability, such as were developed in Adjustment with a Human Face[42] have ignored disabled people and disability. The World Bank's 1990 World Development Report on Poverty made no mention of disability, although it did refer to the relationship between poverty, malnutrition and disease. More recent documents are equally bereft of any consideration of disability. The 2000 Human Development Report of the UNDP, for example, contains compendious data on all aspects of the human condition, with the exception of disability, on which there is nothing [43]. In a 320 page UNCTAD report published in 2002 on poverty in the least developed countries, for example, there is but a single reference to disability.[44]

[40] HM Government, Eliminating World Poverty: A Challenge for the 21st Century. *White Paper on International Development*, London, 1997. HM Government, Eliminating World Poverty: Making Globalisation Work for the Poor, London 2000.

[41] DFID, Halving World Poverty by 2015: economic growth, equity and security. DFID, London September 2000, p. 27.
[42] Cornia, Jolly & Stewart, Adjustment with a Human Face, Oxford University Press, Oxford, 1985.
[43] UNDP, Human Development Report, 2000. UNDP, New York, 2000.
[44] UNCTAD, The Least Developed Countries Report 2002. Escaping the Poverty Trap, Geneva 2002, p.77.

6.3. The international development targets agreed by the membership of the United Nations relate to economic well-being, to social and human development, and to environmental sustainability and regeneration. They include a commitment to a reduction by one half in the proportion of people living in extreme poverty by 2015, universal primary education in all countries by 2015, demonstrated progress towards gender equality and the empowerment of women by eliminating gender disparity in primary and secondary education by 2005, a reduction by two-thirds in the mortality rates for infants and children under age 5 by 2015, a reduction by three-fourths in maternal mortality by 2015, and access through the primary health-care system to reproductive health services for all individuals of appropriate ages as soon as possible and no later than the year 2015.

6.4. While not amenable to quantification, there is a range of qualitative elements of development that are essential to the attainment of the quantitative goals. These include democratic accountability, the protection of human rights and the rule of law. There is no reference to disability.

6.5. There are many reasons why disability has remained on the margins in thinking about development. We contend that a central factor has been the dominance or hegemony of a medical conception of disability, in the development field as well as more broadly in society. As we have argued above, while there is an increasing recognition of the complex social factors surrounding disability, these are generally viewed as contingent not central.

6.6. This leads to the idea that the 'real' work needs to be in the hands of professionals qualified to 'deal with' disabled people. Such a conception not only dis-empowers disabled people (effectively disabling them further), it also strongly mitigates against more inclusive development policies. This, we believe, is demonstrated by the complete absence of a disability perspective in the mainstream poverty-reduction initiatives.

7. DFID's disability strategy: learning from others

7.1. DFID's disability strategy

7.1.1. Although we are critical of the working definition of disability in DFID's recent paper/report on disability, poverty and development, the publication of that paper/report marks an important first step in the recognition of the issue. There are many excellent ideas here, especially with respect to empowerment, a central role for disabled peoples' organisations and the adoption of a rights-based approach to disability and development. We also fully support the proposal to adopt a twin-track strategy - already showing itself to be successful within development policy and practice in tackling the multifaceted nature of the exclusion of women.

7.1.2. However, it seems that besides publishing the paper itself, and setting up the KAR programme on disability and healthcare technology, little is being done at the moment to put the report's recommendations into practice

systematically and comprehensively within DFID. Disability remains institutionally as well as conceptually and practically marginalised, and responsibilities fragmented within DFID itself.

7.1.3. We believe that until this is changed it will be difficult both for DFID to address disability and development effectively and for the KAR Programme on Disability and Healthcare Technology to have the broader institutional structure and support it needs to work effectively.

7.1.4. The role of the KAR Programme in providing a framework for the promotion of research and knowledge on disability, and as a mechanism for the dissemination of the findings and conclusions of its funded programmes and others, will be limited if it is not able to draw on and feed back into an active and committed development agency, capable itself of highlighting and mainstreaming disability issues as part of the development debate. There must even be some doubt about the continuation of this valuable programme unless the work it does is incorporated within the wider policy and practice of DFID.

7.1.5. We believe that, if DFID is serious about integrating disability within its mainstream development approach, then the disability-equality approach needs to be drawn through all their policy and project initiatives. Mainstreaming gender has proved largely successful; the same approach could be adopted for disability.

7.1.6. Given the close links between disability and poverty, the millennium goals with respect to poverty – and all other major themes – need to be re-cast in such a way that disability figures throughout, both as a cross-cutting theme and as a specific issue. It is perhaps a sign that some in DFID at least recognise the importance of this approach that the Civil Society Challenge Fund explicitly refers (in its May 2002 guidelines) to 'disability' as one of the issues that proposals to the Fund are asked to address.

7.1.7. This means that it should figure at all levels, in global strategy and in overall and country programme aid, in Poverty Reduction Strategy Papers (PRSPs) and in Sector-Wide Approaches (SWAps). The Disability, Poverty and Development Paper should be revised (incorporating a more sustained analysis based on the social model approach, and drawing on lessons from other development agencies and disabled peoples organisations) or a more ambitious strategy document developed and its recommendations adopted throughout DFID.

7.2. Learning from others

7.2.1. Two other bilateral development agencies, USAID and NORAD, have been working towards a more coherent approach to disability and development in the last few years, as have several major INGOs, including

Save the Children UK. A brief consideration of these initiatives might be helpful to DFID (for further details see Appendices 7,8 and 9)[45].

7.2.2. USAID has increasingly recognised the need to integrate disability as an issue within its aid and development strategy, and since 1996 has been trying to develop a more inclusive approach to disability issues. In its 1998 report on policy implementation[46] it explains the key reasons behind the new policy initiative:

> It was recognized that the needs of PWDs[47] are the same as the needs of other constituencies with whom USAID works. Segregation of PWDs in USAID activities would tend to increase discrimination among our ranks and in the countries we serve. Consistent with our participation efforts, the Team recognized that to be effective, programs must be constructed to include PWDs at all stages of implementation.

7.2.3. In order to carry out this programme they established both a central disability team and moved to ensure that each USAID mission devised a disability plan and established links with local disabled-peoples' NGOs. The policy was backed up by plans for disability equality training for the organisation.[48]

7.2.4. For various reasons, most significantly funding and reorganisation, the outcome of USAID's policy has been less successful than hoped.[49] However, we believe it offers some extremely useful ideas, particularly with respect to the need for comprehensive disability equality training and the devolution to the mission level for project identification, implementation and assessment.

7.2.5. The Norwegian government has also developed a strong disability policy initiative. In so doing, it has also worked with the wider Nordic group. The NORAD report on inclusion of disability in their development programme[50] makes many of the same points as does the USAID report.

7.2.6. With respect to poverty, the report states that "poverty alleviation in all areas or sectors is the key principle of Norwegian development co-operation. Disabled persons therefore, who are often over-represented amongst the poor, constitute an important target group for development assistance." Besides advocating the need disability equality training for their staff, their plan sets out a number of important guidelines, including:

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[45] For more detail, see Appendices 7, 8 and 9 and original documents cited below.

[46] USAID, First Annual Report on Implementation of the USAID Disability Policy, December 23, 1998

[47] 'PWDs = People with Disabilities'. As we have indicated we do not recommend adoption of this term, and are particularly concerned about the use of the de-personalising acronym

[48] For extracts of USAID's disability policy see below Appendix

[49] USAID, Second Annual Report on Implementation of the USAID Disability Policy, February, 2000.

[50] NORAD, op.cit.

- The rights of persons with disabilities must be an integral part of the dialogue with the authorities in partner countries.
- NORAD will draw up a plan for the operationalisation and use of measures in the efforts to provide bilateral aid to persons with disabilities.
- NORAD's co-operation with the organisations of people with disabilities will be further developed
- NORAD will ensure that assistance to persons with disabilities is clearly indicated in management and reporting systems.

7.2.7. Several INGOs, including Save the Children UK, have also begun to consider disability issues more seriously in recent years. SCF UK has adopted a twin-track approach to disability since 1993, integrating disability into all areas of its work and developing further its specific disability programmes, including Community Based Rehabilitation (CBR) programmes and projects. It developed a Global Disability Strategy in 1998, and, between June 1999 and July 2000, undertook a review of all work relating to disability. In its Global Review Seminar in 2000, SCF UK discussed the global review of their CBR programme worldwide.

7.2.8. CBR is defined by SC UK as 'a strategy for promoting the rights of disabled children, and the survival and development of disabled children within the family and community', having broadly adopted as a definition of CBR provided by the Joint Position Paper of the ILO, UNESCO and WHO in 1994: "CBR is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities".

7.2.9. We have not tried in this paper to review the CBR approach in theory and in practice as it relates to disability, although this is clearly an extremely significant and relevant area of concern. There is a very large number of agencies, international, national and local, across the world undertaking what they refer to as CBR programmes; but there is a very wide range of variation between these, both in terms of conceptual approach and design, and in terms of implementation.

7.2.10. Many are little more than medical outreach programmes, some are more concerned to involve the local community in their programmes and a very few have begun to adopt a holistic social community development framework within which to situate their analysis and assessment of disability and impairment. Here we simply draw attention to the experience of SCF UK, which we consider to be an example of CBR 'best practice'.

7.2.11. For SCF UK, participation is a central concept and therefore 'CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education,

vocational and social services'[51]. Interestingly, the SCF UK Global Review itself adopted a participatory methodology, but it was agreed that "the approach was generally evaluated to have been inclusive and successful, with two main exceptions: the initial 'top-down' system for disseminating information and communication was ineffective, and the seminar lacked sufficient representation from primary stakeholders, especially disabled children and young people, despite extensive efforts to maximise accessibility".

7.2.12. The review itself, however, provided valuable information and insights and led to several specific recommendations, including recommendations for disability equality training and a twin-track approach to disability in development.[52]

7.2.13. Both the US and Norwegian cases also merit close investigation by DFID with respect to implementing its own proposals on disability. There are two aspects that we feel are of particular importance – disability equality training and decentralised, in-country project development.

7.3. Future directions for DFID

7.3.1. No one would think of undertaking project assessment without the requisite training and experience. The same should apply to disability. This is especially true as most people still equate disability with impairment and are, therefore, more likely to feel it is the provenance of experts and/or 'special' provisions. These attitudes need to be changed if practice is to be changed and disability integrated into DFID's mainstream development polices and practice. The need for well-structured and professionally delivered disability equality training is, therefore, paramount.

7.3.2. Looking at the other arm of the twin-track approach – targeted disability projects such as those supported by KAR - we feel it would be better to ensure that decision-making takes place in such a way that brings it more directly in touch with 'the field' and emphasises more the combined 'action-research' focus of such projects. This would be of great advantage to local researchers and disabled peoples' organisations (DPOs), who at the moment are substantially disadvantaged by a process which is heavily weighted towards native English speakers and established organisations, usually based in the UK or Europe and run by non-disabled people.

7.3.3. It is recognised that DPOs are not the only organisations or institutions which may legitimately initiate action-research, but unless other organisations work closely with DPOs or groups of disabled people (and demonstrate their commitment to integrate such collaboration into their approach and methodology) they must run the risk of working, if not 'from the top-down'; at

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[51] SC UK, Community-Based Rehabilitation: global review and seminar report, November 2000, p. 7; Community-Based Rehabilitation for and with People with Disabilities, Joint Position Paper, ILO, UNESCO, WHO, 1994.
[52] See Appendix 2

least working from 'the outside'. Some DPOs would, of course, need support from DFID or from other recognised specialists in developing and presenting submissions as well as in identifying technical or other experts to facilitate projects. As mentioned above, such specialists should be 'on tap, not on top'.

7.3.4. One important result of the shift of emphasis towards DPOs (or at least towards collaboration of researchers and activists in design, planning, implementation and evaluation), would be to empower disabled people and their organisations at the grassroots and ensure not only that they were in control of the process from the onset, but also that outcomes met real needs. In a recent discussion with the head of USAID's disability team we were told that they were actively considering a somewhat similar approach.[53]

7.3.6. DFID's disability and development agenda should, we suggest, be built on a social model foundation and its relevance for government policy more generally – including domestic policy (the importance of giving greater attention within the government's Social Exclusion Unit, for example, to disability issues) - be explained and elaborated. This should be a priority for the future. DFID's strategy for disability and development should be based on a) a coherent vision of how disability reduction relates to the millennium goals and b) a twin-track approach in which disability is both given its own specific institutional priority and is treated as a cross-cutting issue – much as gender has been - and 'mainstreamed' into all development policy and practice.

7.3.7. This would mean creating a cross-sectoral and cross-thematic Disability and Development Unit with a clear brief and identity of its own, and also building disability as an issue into the policy-making, planning and programming of all other sectoral and thematic units and divisions. The equivalent of Green and White Papers on disability and development could then be developed, and disability issues could be built into Country Strategy Papers and PRSPs.

7.3.8. Given the importance of the specific economic, social and cultural context of disability, DFID should adopt an approach which in practice enables decentralisation to take place in funding and programming, probably down to country level, while maintaining an overview through the work of the Disability and Development Unit. This Unit would have its own budget allocation for carrying out or for commissioning research and also M&E and impact evaluation – perhaps through a KAR programme.

7.3.9. Each country development strategy should include a section on disability and development, as an integral part of their overall vision and strategy for development in the particular country concerned. **This implies that trained staff with expertise in disability, appropriate research methods and the relationship between them should be in place.**

7.3.10. Each DFID country office should increase its capacity (identifying a member of staff – probably in the social development area - as disability

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[53] Telephone conversation with Janet Allem, USAID. 13/08/02.

adviser/officer or in larger countries a disability unit) to ensure that all known appropriate organisations and groups be informed about the Programme and invited to make proposals, and also be advised on how to develop the appropriate research design and approach, or put in touch with an appropriate 'partner' with complementary expertise (in research, project management or whatever) to ensure that specialists may be 'on tap'.

7.3.11. We recognise that one disadvantage of a totally decentralised, country-based approach is that it would tend to preclude comparative or regional studies and projects. However, this does not have to happen if the international NGOs are encouraged to work closely with local DPOs, as many of those who were successful in KAR Disability and Healthcare Technology's first funding round did, in developing their projects. There is also the possibility of retaining a fund centrally for regional or cross-country comparative projects, like the KAR programme, which emphasises knowledge and research rather than implementation.

7.3.12. Following the interest of DFID expressed at the time of the preliminary presentation in June 2002, we wish to suggest that, in future, all processes and procedures relating to disability and development be embedded within a clear and coherent DFID strategy. It is our impression that, despite an important start having been made, DFID has not yet developed a coherent strategy with respect to disability and development.

7.3.13. It may be that, in the short run, the KAR Programme can contribute to the development and elaboration of such a strategy. Indeed it might be considered that this Working Paper represents just such an initiative under the KAR Disability and Healthcare Technology Programme, and one which should now be followed up.

8. The KAR Programme

8.1. The KAR Programme is undoubtedly an exciting and important funding innovation. It covers a wide range of sectors and issues in its various sub-programmes. The KAR Programme on Disability and Healthcare Technology is no exception. It is a valuable source of funding for innovative, action-research projects which might not otherwise be funded. We would recommend that, in line with a higher profile for disability generally within development policy and practice, the allocation of funds, to support studies on disability, managed through this vital Programme be significantly increased.

8.2. One of the major difficulties, however, is that the programme definition links disability explicitly and exclusively with healthcare technology, which makes it all the more difficult to break out of the 'disability/impairment is a physical/mental health issue to be addressed by health professionals and healthcare technology' perspective and to establish disability as a cross-cutting issue under the broad heading of poverty and social exclusion.

8.3. How far this structure and effective division of labour can be re-considered and re-organised, is not clear to us. It may be that the PAG, which currently includes the WHO, as well as other specialists, could effectively operate as a two-panel group, with one panel devoted to disability in the broad sense argued for in this Paper, and one devoted to healthcare technology.

8.4. All of our preceding remarks addressed to DFID's broader strategy on disability and development suggest that, while it is extremely valuable to have funds that can be allocated under the KAR Programme to projects that are essentially for research and knowledge creation/dissemination – for innovative projects – by an externally selected organisation (or organisations), there is a danger that projects under this KAR Programme will not benefit from or contribute to a mainstream DFID commitment to disability and development unless there is a stronger commitment within DFID generally to disability as a cross-cutting issue.

8.5. Until this commitment finds institutional form (as recommended by this Paper), however, the KAR Programme should be considering how best to raise the profile of disability in DFID in the meanwhile. One possibility might be to support a specific action-research programme or project, or series of initiatives, based on the kind of framework developed in this Working Paper, designed specifically to do just that.

8.6. Such a programme or project, or series of initiatives, might involve (among other things) a series of interviews, workshops, training sessions and other modes of interaction with key DFID staff, leading to very specific changes in procedures, working practices and 'good practice' across DFID, in London and abroad.

8.7. In the meanwhile, also, we suggest some re-consideration of the procedures currently being used for the assessment and selection of projects to be funded under the KAR Disability and Healthcare Technology programme.

9. Assessing KAR projects: procedures and criteria

9.1. The current procedures for assessing and selecting projects submitted to the KAR Programme involve DFID contracting out the process to external institutions (at the present time, GIC Ltd and HealthLink Worldwide), on the basis of a process of tendering for the job of managing the programme.

9.2. The advantages of such a system are clear (competitive tendering, independence of selected institutions, specialised knowledge and expertise, focus, etc.), but it raises questions regarding the precise relationship between the contracting parties and DFID with respect to the collaborative development of a coherent and systematic approach to disability and development and to maintaining an effective information flow from projects in the field.

9.3. The KAR Programme Newsletter is valuable, but more is probably needed to ensure effective dissemination of ideas, experiences, lessons learned and 'technology transfer' from KAR Programme projects into DFID and evolving thinking on disability and development from DFID into the programmes and projects funded.

9.4. The Programme aims to support the development and application of healthcare technologies and infrastructure and to minimise the detrimental effect of disability on the lives of many poor people in developing countries. It defines technology as including processes and management practices, organisational and supportive systems, and the knowledge associated with these.

9.5. To ensure that the new initiatives financed by the programme are effective in improving the lives and health of poor and disabled people in developing countries, the programme further stresses that the technology should be widely applicable in a range of developing countries at an affordable cost. It must be possible to scale up technology that has been successful on a small scale to a level big enough for it to make a difference. It must provide sustainable results and be replicable in different environments.

9.6. Additionally, if the widespread adoption of technologies is to be achieved, it is essential that information about the lessons learnt should be widely disseminated and that the knowledge associated with its use should be widely shared. For this reason, organisations receiving funding under the programme undertake to ensure that the results are disseminated as widely as possible.

9.7. The question of who precisely is to review and select the projects and what qualifications they have is the first to be answered. The Programme is currently managed by two institutions based in the UK. Again, the advantages of this are evident: proximity to DFID HQ (with implications for maintaining communications, ensuring dissemination of information, etc.). But it makes it inevitable that the selection process is at some 'distance' from the field where the proposed projects are to be undertaken or implemented.

9.8. Although site visits are in theory possible, there is inevitably strong pressure for short listing to take place first, and thus for the initial crucial selection to take place on the basis of written submissions – which, unless complemented in some way by references or other additional information, tends to privilege those organisations and institutions best able to produce 'a good proposal' (well presented, in good clear English, etc.) but not necessarily those best able to design and implement an effective and sustainable disability project.

9.9. It is also likely, given the global scope of the programme, that the dissemination of information regarding the Programme itself and details of how to make an application is unavoidably somewhat limited. It would be more difficult for an indigenous NGO or DPO to learn about the possibility of proposing a project than an international organisation or one based in the UK,

or at least 'in the loop' (already linked to a Northern institution or INGO) as far as the circulation of information is concerned.

9.10. Decisions on project eligibility are currently made by a Programme Advisory group (PAG), which comprises representatives from DFID and the WHO, specialists in disability and healthcare technology, and the programme managers (Healthlink Worldwide and GIC Ltd.) The PAG and PMC review the portfolio of projects funded to ensure that they provide adequate coverage of both themes (disability and healthcare technology) and of the various priority areas within Theme 1 (improved healthcare technologies and infrastructure for poor people) and Theme 2 (minimising the detrimental effects of disability on the lives of poor people)". It is not clear, however, how far this affects the initial selection of projects.

9.11. There is currently a special provision for small projects, costing up to GBP 20,000 each, with a preference that these come from developing country proposers. This seems tokenistic – if it is considered important to encourage proposals from developing countries, then this should be built into the formal criteria and given adequate weighting. We are not convinced by this 'ring-fencing' and would recommend that, in general, preference be given simply to the best proposals, judged in terms of their likely effectiveness and impact, sustainability and replicability.

9.12. The specific involvement of WHO and the linking of disability with healthcare technology, as we have already argued, also gives a definite bias to the overall perspective on what constitutes disability and what constitutes the most appropriate kind of project for funding. We recommend therefore, a progressive 'un-coupling' of disability and healthcare technology, with an initial divison of the PAG into two panels, and the eventual possibility of a KAR on Disability alone.

9.13. Those in the PAG and PMC reviewing the portfolio are evidently considered to have the required expertise and experience to make a reliable judgement. We have to say, however, that we consider this process very far removed from the grass roots at which the majority of these relatively small projects being proposed will operate.

9.14. We see advantages in a more decentralised process, albeit with a KAR Programme selection committee overseeing the process; but one with more real decision-making power closer to 'the field'. It may be that the establishment of regional or national panels of 'locally-based' assessors (with relevant experience, professional expertise and/or disability equality training), providing a direct input (on the basis of site visits, discussions with the project proposers and other relevant stakeholders (including disabled people and DPOs), would be possible.

9.15. Whatever the detailed procedures agreed, the objective is to increase the opportunities for the critical evaluation of proposals by those more familiar with the local social and 'political' context and local structures of disability – and with the project and its proposers - than at present.

9.16. Those involved in the selection process at all levels (from the local assessors to the PMC and PAG) should have themselves had disability equality training. Ideally, in the future, all of those in DFID or contracted by DFID to undertake work (policy, research, management and selection of projects, etc.) relating to disability would be required to undergo a suitable training programme. Representatives from British disabled-peoples' organisations familiar with development issues should be included as selectors along with experienced researchers, capable of judging the feasibility, effectiveness and sustainability of all projects proposed

10. Judging KAR applications

10.1. 'Nothing for us, without us'

10.1.1. DFID's own policy proposals call over and over again for a rights-based approach, the empowerment of disabled people and their participation in development projects.[54]

> "Positive changes in the situation of people with disabilities are dependent on the actions of governments, and the empowerment of people with disabilities themselves."

> "Benefits are likely to be greater when services for people with disabilities are provided within existing social, educational, health and labour structures in society, and where procedures are established to permit effective participation of persons with disabilities in decision-making processes."

> "A rights-based approach to disability and development implies a right to self-representation. The rights of people with disabilities are best promoted by people with disabilities themselves."

10.1.2. The case studies we have examined - Whirlwind Wheelchair, Motivation, Projimo, The Jaipur Limb Campaign, etc. (see Appendices 3,4,5 and 6) - appear to confirm the notion that projects with a strong practical (technical) focus designed by or with disabled people seem to have a much better chance of meeting real needs as well as being sustainable and cost-effective.

10.1.3. Whirlwind Wheelchair call this process 'descriptive design', which they contrast with the 'prescriptive design' which imposes a particular design on users. For WWI, who produce the whirlwind wheelchair (see Appendix 3), use of the descriptive design process derives naturally from the socio-economic situation in developing countries and from the complex nature of disability itself. But it is also very significant that, "for a product like a wheelchair, that can be prototyped quickly and inexpensively, the descriptive design process is efficient and cost-effective".

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[54] DFID, op.cit, pp.11-13.

10.1.4. This suggests that all projects, whether research-based or applied, should be firmly rooted in the expressed needs and demands of disabled people and thus be essentially demand-led. That is, ideally, projects should have their genesis with disabled people and their organisations, identifying their own needs and then, if and when necessary, being provided with the technical support and/or advice as to how best to achieve their objectives. There is more than one way to achieve this, as shown by the different emphasis of WWI and Motivation in meeting disabled peoples' demand for wheelchairs.

10.2 The 'fast track selections'

10.2.1. An initial group of six research projects was approved for funding under the fast-track procedure in December 2000. The projects selected included

- Training of wheelchair technologists (Tanzania)
- Health information systems processes and technologies (Malawi)
- Medical equipment maintenance training (The Gambia)
- Research into the economic impact of uncorrected vision (Ghana and India)
- Creation of a Global Knowledge Network
- International Good Practice on Disability

10.2.2. This was followed by a competition, which ended in May 2001. This 'first round' proper was followed by a second round in 2002.

10.3. The first round

10.3.1. The first round of applications for the KAR Disability and Healthcare Technology Programme took place during 2001 and involved a two stage process, A *concept note* was called for and all concept notes received were reviewed. A short list was drawn up and those applicants shortlisted were invited to prepare *a more detailed proposal* for consideration. The review at each stage involved a selection panel and the panel applied a set of criteria as an aid to decision-making. The selection panel consisted of personnel from Healthcare Worldwide and GIC Ltd, plus selected specialists

10.3.2. The 50 or so concept notes received were extremely varied in approach, content and location of proposer and project. According to the Programme newsletter, 'Disability and Healthcare Technology', a further twelve projects were selected in the first round, "reflecting a good balance between small and large projects, disability and healthcare technology and the three categories (projects that develop a new technology, adopt a newly developed technology or contribute to the wider use of a successful technology) as well as covering a broad geographical area.

10.3.3. The disability projects selected (some concept notes although approved were not re-submitted as full project proposals) included:

1. ***Field testing of the "Access Portfolio": The Early Identification and Intervention for Children with Disabilities***, submitted by the Disability and Rehabilitation Team (DAR) at the WHO.

2. ***Capacity Building in Community Based Rehabilitation for Children with Disabilities, Kenya*** – by Voluntary Service Overseas, Kenya Programme Office

3. ***A new instrument to assess the impact of a community-based intervention for children with communication disabilities in Kenya***, a team comprising the Centre for International Child Health in London , KEMRI/WTRL in Kenya and the Neurosciences Unit, London.

4. ***WorldMade****,* By the Motivational Charitable Trust, Bristol

5. ***Prefabrication of Knee Ankle Foot Orthosis (KAFO) for low cost mass production and rapid fitting***, by the Jaipur Limb Campaign, London and Mobility India, Bangangalore

10.3.4. One of the successful projects is specifically concerned with capacity building, two are concerned to develop approaches to needs assessment and two are concerned with the production of appropriate equipment. The last two involve organisations with a proven track record of work with wheelchairs and limb technology respectively. (Further details of all five of these 'successful projects' are provided in Appendix 10).

10.3.5. The selection process involved the review of concept notes, followed by the review of project proposals. These were subject to assessment, according to agreed criteria and by completion of the KAR assessment forms (see Appendices 11 and 12). No site visits were undertaken.

10.3.6. The guidelines for selection of projects contained in the 'criteria for project selection' (see Appendix 11) certainly imply that priority will be given to projects which:

> "are consistent with an empowering and inclusive approach to people with disabilities; a key component of this will include listening to the views of disabled people in any needs assessment carried out as part of the process of identifying needs for new technologies;"[55]

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[55] **Ibid.**

The actual project criteria for KAR as set out in the pro-forma[56], however, reflect neither this approach nor DFID's own emphasis on empowerment and participation. Nowhere in the seven percentage-based criteria is there mention of project genesis or control over the process, and only passing reference to the specific role of disabled people in the process. In the absence of site visits or interactive discussion with the project proposers the decision-makers were obliged to rely on the written proposals, the criteria applied and the weighting of different identified components.

10.3.7. The general formulation does not seem to be carried through into the design of the pro-forma or the actual weighted criteria applied in the selection of projects. This reveals the general formulation to be no more than tokenistic, especially when we consider that it might be reasonably expected that the supposed beneficiaries of any project should be consulted at the very least and that a needs assessment should be undertaken.

10.3.8. Not only the procedures, as indicated previously, but the criteria used risk biasing the selection procedure towards favouring established 'known' charities and Northern-based professional institutions which routinely undertake projects. A 25% weighting (one of the highest) is given to teams which have strong track records. Very few Southern NGOs will have this kind of apparent strength (although a few – eg the Jaipur Limb Campaign - do).

10.3.9. While recognising that effective design and management of projects is a legitimate objective for KAR and for DFID, with 'cost-effectiveness' emerging strongly even at this stage as a prime concern, a greater focus on the involvement of disabled people in the design and implementation of the project is equally likely to produce an appropriate and suitable project in the long-run, also meeting objectives of sustainability and long-term cost-effectiveness.

10.3.10. In short, the KAR policy and practice of selecting projects risks reinforcing the traditional 'top-down' approach to development and disability, maintaining disabled people in the role of passive recipients of services thought up, designed and controlled by experts. We recognise, however, having said this, that the first round of project selection ended with five projects, all of which appear to us to meet the criteria that we would argue are of crucial importance (for details of these projects, see Appendix 10).

10.4. Second Round

10.4.1. One of the authors of this Working Paper was involved in the selection process for the second round of applicants. A general criticism that he made of the proposals was the apparent lack of expertise in action-research or 'applied research' demonstrated by many of them: "Many of the proposals, while laudable in some respects, showed no awareness of monitoring and evaluating their own work or, even in the case of DPOs, how they might consult and include disabled people. Good quality qualitative research…is not

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[56] See Appendix 12

ivory tower, is broadly based and consultative, is not done to people but with them".

10.4.2. Below we suggest how the criteria might be changed, if the selection process remains broadly the same. Indeed, the main demand outlined in the brief from Healthlink was for our team to set out "…clear recommendations for the KAR programme on which funding decisions can be made." This included the following:

- ❑ Criteria to be considered when making funding decisions for disability projects within the programme
- ❑ Relative weightings to be applied to these criteria, including, if possible, some kind assessment tool (with weightings) which could be used by assessors during the project assessment process
- ❑ Recommendations of particular areas were gaps exist in this field where the KAR programme could commission specific work

10.4.3. First, we would suggest that a distinction should be made between overall goal and specific purpose of project, where the goal for all projects would be: 'significantly reducing disability and enhancing the capacity of disabled people to participate fully as equal citizens'. The specific purpose would then be broadly as 'project goal and purpose' is now.

10.4.4. The project selection criteria should give more weight to the relationship between the project and the disabled people (and DPOs) who are to be involved and who are to be the intended beneficiaries. This could be achieved by a) a specific weighted item on its own, b) additional weighting given to 'methodology', which at the moment is the only heading which explicitly refers to 'input of beneficiaries in the project', or probably better, included explicitly in **all** other headings. In all of these, the level and kind of active involvement of disabled people and specific links with existing DPOs (or, if these are not available, appropriate NGOs or other institutions) should then be explained and demonstrated.

10.4.5. All project proposals should include explicit mechanisms whereby the claims made at the outset of the project (in the proposal) can be monitored and verified. We note that while some of the projects selected in the first round included logical frameworks and defined the 'verifiable indicators' and 'means of verification' to be used to monitor and evaluate outcomes (not just outputs) and impact, not all did. We suggest that all projects should demonstrate how they will monitor and evaluate the project and that the participation of disabled people in the design, planning, implementation, monitoring and evaluation be weighted heavily.

10.4.6. The capacity of the proposers to undertake effective action research or applied research, and to work with disabled people would appear to be of critical importance. Judging this from such a distance on the basis of written submissions only, is indeed a difficult task. Those involved in the selection process should, in our view, be able to make extended site visits if needs be;

this would be facilitated by a greater degree of decentralisation in the selection process and the involvement of DFID disability advisers and social development specialists in country together with experienced researchers and DPOs in the selection process at national level.

10.4.7. These are just a few of the main comments we would wish to make regarding the weighted project selection criteria. Although these could be modified and refined further, this would not get to the heart of the problem, which we feel is to be found in the centralised, London-based selection procedures, supervision and management of the KAR Disability and Healthcare Technology Programme.

11. Specific conclusions and recommendations

Number	Recomendations	Time Frame	Responsibility
1.	For DFID as a whole	Long – 3-5 years	Seniorstaff/ various departments
2.	For DFID concerning KAR DHT Programme	Short/Medium – incorporate into any proposal to re-tender management of programme	DFID staff members with specific responsibility for KAR Programme
3.	For Programme Managers	Short – incorporate into C2 assessment and funding decisions	PMC/PAG
4.	Future research	Short – projects identified could be commissioned as part of funding committed to C2	PMC/PAG

11.1. For DFID as a whole

1. We recommend that DFID adopt an approach to disability, poverty and technology which recognises that these are all the outcomes of complex and dynamic social processes and clearly distinguishes between impairment and disability. As Save the Children insist, "it is the way society responds to… impairments which is disabling, responses which include discrimination, negative attitudes and exclusion".

2. We recommend that DFID recognise and assert the importance of technology not as a set of things or infrastructures but as a process involving the application of knowledge to produce solutions to problems. We also recommend DFID recognise that all technology or technologies which reduce barriers to inclusion and participation (not only assistive or specifically 'healthcare' technologies) can be seen as a basic human right.

3. We recommend that DFID promote a twin-track approach to disability, as has been done with gender. All DFID-supported initiatives or projects should be able to demonstrate that they are truly inclusive of disabled people (the recent initiative of CSCF is particularly welcome in this regard). Significant, additional funds should be made available to support disability-specific initiatives.

4. We recommend that DFID should establish a Disability and Development Unit, with its own Disability KAR Programme. Alternatively, it should create a specific task-force or unit with a prime responsibility for disability, whose activities would cut across all MDGs. Disability, like gender, would be regarded as a specific but cross-cutting issue.

5. We recommend that DFID ensure that each country development strategy or PRSP include (provision for) a focus on disability.

6. We recommend that DFID embark on a programme of disability equality training for its staff. This is essential if disability is to be effectively mainstreamed within DFID's work. Those working specifically with disability and/or involved in the selection of disability programmes and projects for funding should be involved in such training as an urgent priority.

7. We recommend that DFID recognise that the links between disability, poverty and technology are complex and that more action-research is required in this area.

11. 2. For DFID re the KAR DHT Programme

1. We recommend that the value of the KAR Programme for disability action-research and support for new initiatives be recognised and that increased funding be allocated, if possible, to this initiative.

2. We recommend, however, to DFID and to the PAG, that the disability and the healthcare technology aspects of the present programme be separated out in future (specifically for any re-bid management contract). The new Disability KAR Programme should focus on all aspects of disability and not technology only. The future of the HCT component of this programme is beyond the scope of this Working Paper.

3. We recommend that DFID specify in any new tender for the management of the KAR Programme that it expects to see a more decentralised management process in the next phase of the programme.

4. We recommend that DFID work with the PMC to establish ways in which the programme can influence DFID's main strategy more explicitly.

5. We recommend that DFID assess any proposals for management of the KAR Programme in terms of who assesses projects being considered for funding and how they carry out the assessment, placing emphasis on the involvement of local experts, disabled people and their organisations, and on non-written means of assessment, such as site visits[57].

11.3. For the Programme Managers

1. The KAR Programme should adopt the approach to disability and to technology suggested in the Working Paper. That is, that disability results from the social barriers created by various processes of social exclusion; and that technology is not a set of things, it is a process of the application of knowledge to produce solutions to problems.

2. The Programme should not try to make funding decisions on the basis of statistics relating to the prevalence of impairment, but on the basis of the potential for impact (numbers of beneficiaries, sustainability, potential for replicability and changing policy and practice more widely).

3. The Programme should establish an appropriate balance between projects selected through competition and commissioned work. We would recommend increasing somewhat the proportion of commissioned work to enable the Programme to 'fill gaps' and ensure coverage of urgently needed action-research, while at the same time allowing initiatives to come from 'below'.

4. Greater priority should be given to those projects which clearly have the active involvement of disabled people and their organisations, and can demonstrate, through their presentation of research methodology and project monitoring and evaluation, their capacity to deliver high quality and sustainable action-research.

5. The programme should make more use of local assessors and site visits. It might be possible to constitute a panel of, say, 10 local assessors from different geographical regions who would be involved in some way at both Concept Note and Proposal stage and who might carry out site visits at Proposal stage.

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[57] Each DFID country office should increase its capacity (identifying a member of staff – probably in the social development area - as disability adviser/officer or in larger countries a disability unit) to ensure that all known appropriate organisations and groups were informed about the Programme and invited to make proposals, and also advised on how to develop the appropriate research design and approach, or put in touch with an appropriate 'partner' with complementary expertise (in research, project management or whatever) to ensure that specialists were 'on tap'.

6. PMC should ensure that everyone involved in the assessment of Concept Notes and Proposals, including PMC staff, PAG members and local assessors have undergone Disability Equality Training.

7. The programme should in the short run separate the PAGs for disability and healthcare technology (perhaps meeting in the morning and afternoon respectively). WHO should probably not be a member of the disability PAG and current co-chairs could each chair one of the two new PAGs.

8. Weightings for assessment should be changed to increase emphasis on the involvement of disabled people and on the methodology (including production of a logical framework and monitoring and evaluation), and to reduce somewhat the emphasis on the team. Involvement of disabled people and their organisations should be a separate category and not simply part of methodology. All project submissions should provide a logical framework.

11. 4. Future Research

1. An urgent priority is to increase knowledge about practice and to identify 'best practice' as regards disability and development, both in other government agencies and in non-government organisations. In part this may already be covered by the Healthlink Worldwide project approved under the 'fact-track' initiative, but this should be an action-research project in which wide dissemination of the draft findings on an iterative basis would be in-built.

2. Two other 'registers' would be valuable: 1) an International Register of organisations and institutions with a capacity to design and implement innovative projects (including research institutions, NGOs, DPOs and private sector enterprises), and 2) an International Network of Technology Providers for Disability Reduction.

3. This Working Paper was produced on the basis of relatively limited research. It would be cost-effective to commission a more comprehensive study, which would involve a) a review of the literature (and other sources – eg on the inter-net) relating to disability and development, b) a review and analysis of significant programme or project initiatives (involving research and/or implementation), and c) a listing and discussion of country-by-country experience with respect to disability and development. This would constitute a fairly substantial project and could well be published as a book on 'Disability and Development: national and international initiatives'.

4. The area of disability and older people is becoming a matter of major concern in many developing countries as the demographic structure changes. Projects which related to this issue would be a priority.

5. There is some evidence to suggest that many children with impairments die or are hidden. We need to know much more about such children and their early lives.

11.6. **Final Comment**

It is hoped by the authors and contributors to this Working Paper that there will be opportunities in the coming months to discuss the views contained therein with colleagues from DFID and other development agencies, NGOs and private sector enterprises.

Bill Albert
Rob McBride
David Seddon

Overseas Development Group
Norwich September 2002

12. References and Preliminary Select Bibliography On Disability Studies and Disability and Development

References

Tony Barnett & Alan Whiteside (2002) **AIDS in the 21st Century: disease and globalization**. Palgrave Macmillan, London.

R. Bowron (ed) (1998) **Worlds of Difference Supplement**, BBC World Service, BBC, London.

Peter Coleridge, "Disability and Culture", (eds) Maya Thomas & M. J. Thomas, **Selected Readings in CBR, series 1, CBR in Transition.**

Cornia, Jolly & Stewart, **Adjustment with a Human Face**, Oxford University Press, Oxford, 1985.

DFID, "**Exploring the Links between Disability, Technology and Poverty: A Concept**". nd

DFID, **Poverty: Bridging the Gap. Guidance Notes**. DFID, 2001

DFID, **Halving World Poverty by 2015: economic growth, equity and security**. DFID, London September 2000

DFID, **Realising human rights for poor people**. DFID, October 2000

DFID, Disability, Poverty and Development, 2000

Disability Awareness in Action, **Overcoming Obstacles to the Integration of Disabled People**, Copenhagen, 1995

Disability Rights Commission**, Mission Statement,** UK Disability Rights Commission, 2001.

Ann Elwan, "Poverty and Disability. A Survey of the Literature", a background paper for the World Development Report, World Bank, December 18, 1999.

Susan Erb & Barbara Harriss-White (2002) **Outcast from Social Welfare: adult disabilities incapacity and development in rural south India.** Books for Change, A Unit of ActionAid Karnataka Projects, Karnataka**.**

Vic Finklestein, "The Social Model Of Disability Repossessed", Manchester Coalition of Disabled People, December 1, 2001

HM Government, Eliminating World Poverty: A Challenge for the 21st Century. White Paper on International Development, London, 1997.

HM Government, Eliminating World Poverty: Making Globalisation Work for the Poor, London 2000

Hershey and Stephens**, Leadership Development Strategies for Women with Disabilities: A Cross -Cultural Survey,** 1995

ILO and others, **Community-Based Rehabilitation for and with People with Disabilities**, Joint Position Paper, ILO, UNESCO, WHO, 1994

Marks, Deborah (1999). **Disability: controversial debates and psychosocial perspectives.** Routledge, London

S. Miles, "Strengthening Disability and Development Work", BOND discussion paper, Feb. 1999.

NORAD (2000) **Disability in Nordic Development Cooperation: synthesis report prepared for the Nordic Conference.** Prepared for NORAD by Anne Hertzberg, Centre for Health and Social Development, NORAD, August 2000

SC UK, **Community-Based Rehabilitation: global review and seminar report**, November 2000.

Emma Stone, "Disability and Development in the Majority World", in **Disability and Development: Learning from action and research on disability in the majority world**, ed. Emma Stone, The Disability Press. Leeds, 1999,

Elaine Stillwaggon, "HIV transmission in Latin America: comparison with Africa and policy implications", **South African Journal of Economics**, 68(5): 985-1011.

Neil Thin, Mary Underwood and Jim Gilling, **Sub-Saharan Africa's Poverty Reduction Strategy Papers from Social Policy and Sustainable Livelihood's Perspective: a report for DFID**. Oxford Policy Management Group, Oxford, 2001, p. 4. Cited in Alan Whaites (ed) **Masters of their own Development? PRSPs and the prospects for the poor.** World Vision, California, 2002,

UN, Disability Statistics, nd

UNCTAD, The Least Developed Countries Report 2002. Escaping the Poverty Trap, Geneva 2002,

UNDP, Choices for the Poor. Lessons from national poverty strategies 2001

UNDP **Human Development Report, 2000**. UNDP, New York, 2000

USAID (1997) **USAID Policy Paper on Disability**, USAID, 12 September 12, 1997

USAID, First Annual Report on Implementation of the USAID Disability Policy, December 23, 1998

USAID, Second Annual Report on Implementation of the USAID Disability Policy, February, 2000.

David Werner, **Nothing About Us, Without Us: developing innovative technologies for, by and with disabled people.**

World Health Organisation (1980) **International Classification of Impairment, Disability and Handicap (ICIDH).**

Disability Studies

Barnes, Colin (1990). **Cabbage Syndrome: the social construction of dependency**. Tavistock, London

Barnes, Colin & Mercer, G (eds) (1996). **Exploring the Divide: illness and disability.** The Disability Press, Leeds.

Colin Barnes & Geof Mercer (eds) (1997). **Doing Disability Research.** The Disability Press, Leeds.

Len Barton (ed) (1996) **Disability and Society: emerging issues and insights**. Longman, London

Len Barton & Mike Oliver (eds) (1997). **Disability Studies: Past, Present and Future**. The Disability Press, Leeds.

J. Campbell, J. & M. Oliver (1996**). Disability Politics**. Routledge, London**.**

L. Davis (ed) (1997). **The Disability Studies Reader**. Routledge, London.

G. Hales (1996) **Beyond Disability: towards an enabling society**. Sage with the Open University Press, London.

Deborah Marks (1999). **Disability: controversial debates and psychosocial perspectives.** Routledge, London

J. Morris (1996). **Encounters with Strangers: feminism and disability.** Womens Press, London.

Mike Oliver (1990. **The Politics of Disablement**. Macmillan, Basingstoke.

Mike Oliver (1996) **Understanding Disability: from theory to practice**. Macmillan, London.

Mark Priestly (ed) (2001**) Disability and the Life Course: global perspectives**. Cambridge University Press, Cambridge

Tom Shakespeare (ed) (1998) **The Disability Studies Reader: social science perspective.** Cassell, London.

John Swain, Vic Finkelstein, Sally French & Mike Oliver (eds) (1996) **Disabling Barriers – Enabling Environments**. Sage Publications in association with The Open University.

Disability and Development

Peter Coleridge (1993). **Disability and Development**

DFID (2001) **Poverty, Disability and Development**

Susan Erb & Barbara Harriss-White (2002) **Outcast from Social Welfare: adult disability, incapacity and development in rural south India**. Books for Change, A Unit of ActionAid Karnataka Projects, Karnataka.

Barbara Harriss-White (1999), 'Adult disability, poverty and downward mobility: the macro- and micro picture from India', Paper presented to the 1999 Development Studies Association Annual Conference.

Einar Helander, **Prejudice and Dignity: an introduction to Community-Based Rehabilitation**. UNDP.

Emma Stone (ed) (1999) **Disability and Development: Learning from action and research on disability in the majority world.** The Disability Press, Leeds

13. Appendices

1. Authors cvs (attached to main report)
2. Disability Equality Training (attached to main report)
3. Whirlwind Wheelchairs
4. Motivation
5. Projimo
6. The Jaipur Limb Campaign
7. The USAID experience
8. The NORAD experience
9. The experience of Save the Children
10. The selected five projects (round 1)
11. KAR selection criteria
12. KAR pro-formas

Appendix 1

The team consisted of an advisory group of five selected specialists - Dr Ken Cole, Dr Roger Cozens, Ms Victoria Daines, Dr Ray Lang, Mrs Indumathi Rao – and a 'core' group, responsible for the drafting of the Working Paper – Dr Bill Albert, Dr Rob McBride, and Professor David Seddon – the last of whom acted as co-ordinator and overall project manager. The members of the team were selected so as to provide a range of perspectives covering the key areas of expertise identified in the original terms of reference (economics, technical, and disability activists), with the specific addition of gender. Some of the specialists contributed from several of these perspectives.

Dr Bill Albert

Bill Albert, a retired Reader in Economic and Social History at the University of East Anglia, is a former chair of the International Committee of the British Counsel of Disabled People. He is currently the chair of the Norfolk Coalition of Disabled People and Disabled People International Europe's Bio-ethics Committee. He is also a member of the UK government's Human Genetic Commission. He is an experienced disability equality trainer and has worked with disabled people's organisations in Europe and the former Soviet Union.

Dr Ken Cole

Ken Cole is Senior Lecturer in Economics at the School of Development Studies and a member of the Overseas Development Group. He has worked generally on disability issues and recently with a CBR programme in Bosnia-Herzegovina. He has supervised research students working on disability and CBR in India, Bosnia and Malaysia. His publications include 'Human Rights, Development, Disability and Community-Based Rehabilitation', a background paper commissioned by DFID.

Dr Roger Cozens

Roger Cozens is an agronomist/agriculturalist with a first degree in applied biology, an MSc in Agricultural Development and extensive experience working with farmers in Europe, Africa and Asia over 20 years. His special areas of interest include educational and community work. He has spent three years as agricultural officer in Nepal working with disabled people suffering from leprosy and was involved in participatory action-research relating to the adaptation of tools for disabled people. In 1999, he contributed to the International prevention of Impairment and Disability Seminar in Pokhara, Nepal, funded by the Institute of Tropical Medicine.

Ms Victoria Daines

Victoria Daines is a Case Work Manager for the Disability Rights Commission in Manchester. She has a first degree in Law and Sociology from Warwick University and is currently studying for a part time MA in European Law with the University of Leicester. She has worked previously as an employment discrimination lawyer and undertaken research on gender issues, and on disability and education. She is currently a part-time researcher on disability and ageing with the Overseas Development Group.

Dr Ray Lang

Ray Lang is a disability activist. His PhD on 'Perceiving Disability and Practising Community Based Rehabilitation: a critical examination with case studies from South India' was awarded by the University of East Anglia in 2000. During 2001 he worked as a researcher for the Overseas Development Group at the University of East Anglia with David Seddon on a DFID-funded project on 'disability, rights and capabilities'. Currently in the Public Health Policy department at the University of Glasgow, he has a long track record of working for disability NGOs, including what was formerly AHRTAG and is now Healthlink Worldwide. He has published widely in the disability field, including recently on 'The role of NGOs in the process of empowerment and social transformation of people with disabilities', in (ed) M Thomas & M J Thomas, Selected Readings in Community Based Rehabilitation, CBR in Transition. January 2000.

Dr Rob McBride

Rob McBride was formerly Director of International Education in the School of Education and Professional Development, and Co-ordinator of Education for Development in the School of Development Studies, both at the University of East Anglia. He has published widely on educational issues, but has in recent years broadened his expertise to include a range of social development topics. Currently, he is a Research Fellow in the School of Development Studies, an Associate of the Overseas Development Group and a free-lance consultant. He has worked in a number of African and Asian countries.

Mrs Indumathi Rao

Mrs Rao has a first degree in science from the University of Bangalore, training from the Association Montessori Internationale and an advanced diploma in the education of handicapped children from the University of Manchester. She was the founder of the Niveditha Shishu Kendra Integrated Day Care Centre for children with learning difficulties and has been (among other things) Chief Advisor to Niveditha Manovikasa Kendra (a self-help group

of parents with mentally handicapped children), a member of the Task Force to draft public policy on disability for the government of Karnataka State, secretary to the advisory committee to promote the integrated education of children with disabilities in Karnataka State, and South Asian Regional Coordinator of the Community Based Rehabilitation Network. She is editor of several publications produced regularly by CBR Network as well as five booklets, in a series From Panchayat to Parliament, on integrating disabled people into mainstream development programmes. She is co-author (with Einar Helander) of Developing Community Based Rehabilitation Programmes in South Asia and author of 'Seva in Action: a CBR model in India' in Prejudice and Dignity, (ed) Einar Helander. Published by the UNDP.

Professor David Seddon

David Seddon is Professor of Sociology and Politics in the School of Development Studies and former Managing Director of the Overseas Development Group. He has extensive experience of working with poor and disadvantaged people in developing countries, in Africa, the Middle East and South Asia. He has directed several research projects recently in the area of disability and CBR, including a project on 'disability, rights and capabilities' with Dr Ray Lang (as part of a larger project on 'Wellbeing, rights and capabilities' funded by DFID through ESCOR) and designed the project evaluation component of an international CBR programme in five Asian countries, supported by Handicap International and the Christophel Blinden Mission. He is the founder of the Disability and Development Action Research Network(DDARN).

Appendix 2

Disability Equality Training

In a wide variety of fields and situations there are increasingly calls for training about disability. For example, one of the key recommendations in all the codes of practice related to various sections of the Disability Discrimination Act 1995 is for staff to be offered disability equality training (DET). Both USAID and NORAD have made the provision of DET a key feature of their disability programmes. Yet in none of these cases, or in others where DET is recommended, is it said exactly what DET is or what the aims and objectives of such training should be. This is the purpose of this brief appendix.

Traditionally, disability awareness training was about telling and/or showing people what it was like to be disabled. So, some trainers would put participants in wheelchairs or give them semi-specs (glasses modified to simulate particular eye conditions). The rationale behind such training was that through it able-bodied people would be better able to relate to or "deal" with disabled people because they would have an insight into what it was really like not to be able to walk or to be blind or deaf. While this is still done by some trainers, the approach is now widely discredited.

To use a wheelchair for ten minutes is not to understand what it is like to have to use a wheelchair all day, every day. In fact, it may give one a false sense of understanding, something which can be more dangerous then no understanding at all. Second, and most importantly, such training comes directly out of and reinforces a medical-model conception of disability, that is the idea, still widely held in most societies, that disability equals impairment.

Although there are a variety of different approaches to DET currently offered by disabled trainers and training groups in the UK, almost all are based around the social model of disability. This means that rather than impairment being the key concern, as in the example cited above, the focus tends to be around environmental and attitudinal barriers to equal access. Besides the general arguments for the social model, because of its concern with factors which trainees can change in their work practice, DET training which comes out of this model is more effective with respect to outcomes – that is helping staff provide an inclusive, non-discriminatory service.

Much as the social model prioritises barriers to inclusion, social-model DET should not start not by looking at disabled people but rather at participants attitudes toward disability. We favour an approach which concentrates on encouraging people to start somewhere they know reasonably well and feel comfortable with – themselves. Examining their assumptions about how they identify both themselves (what makes them who they are) and others is an important first step in deconstructing disability. This in turn tends to be more productive with respect to valuing difference and creating the appropriate conditions for developing policies, procedures and practices which support equality of access.

The aims and objectives of any DET course will vary depending on the client group. However, in general the aim should be both to get people thinking about their own and social attitudes toward disability, how these might feed through in their work and how in light of all this work practice can be improved.

The argument is that with respect to disability, as with many other things, social assumptions frame perceptions which help determine understanding. This understanding then informs actions or lack of action. So, if the people have a deep-seated assumption that people are disabled by their impairments, and most people do, then they will perceive the difficulty disabled people experience as deriving from those impairments. This understanding of disability may then lead to the idea that the appropriate action is either cure or some other specialised service for which 'experts' are essentially responsible. Through this process disabled people are constructed as 'the other', dependent people for whom special facilities need to be provided. This disablist paradigm is in turn the basis for segregation and social exclusion, all done for the 'best possible motives' – a charitable sense of caring for the vulnerable. Providing the opportunity for trainees to examine their own attitudes and through this do begin to unravel the social dynamics of disability is a powerful method for changing this kind of perception, understanding and practice.

Most DET courses are divided into two basic segments. The first is an examination of personal and social attitudes towards disability, in short how disability is socially constructed. The second is to look at work practice in light of new insights about disability and to start a process of progressive change.

With respect to DET around development, the issues are somewhat different. While participants' attitudes remain a central concern, because of the socio-cultural specificity of disability, trainers need to be sensitive to the significant differences which can be encountered in different countries. For example, in some societies disabled people may be considered pariahs, while in others people with certain impairments might be venerated. Also language and visual representation, powerful indicators of social attitudes towards and understanding of disability, are largely culturally determined and so demand a nuanced interpretive approach. This strongly suggests that when commissioning DET, DFID should be looking not only for experienced disabled trainers who work within the social model, but ones who have also worked in developing countries.

Finally, because DET is so important for any organisation which is committed to best practice with respect to equality, we strongly recommend that DET become a compulsory part of training provision for DFID staff, and for all those involved in the assessment and selection of projects involving disability to be supported by DFID. Experience in both the public and private sector has shown that unless people are obliged to undertake such training, it will be taken up by those who tend to already have a positive attitude towards disability and be ignored by those who do not and are, therefore, in most need of such training.