DEVELOPMENTAL ARTICLES

PERSPECTIVES ON DISABILITY, POVERTY AND TECHNOLOGY

Bill Albert, Rob McBride, David Seddon*

ABSTRACT

The Knowledge and Research (KAR) Programme of British Department for International Development (DFID) has linked 'disability' with 'healthcare technology' and for this reason DFID has been interested in the potential role that 'technology' plays – and can play - in reducing (or possibly in increasing) disability. It is axiomatic that technology plays an important role in affecting the physical environment and the immediate physical circumstances in which disabled people live and work. It can produce built environments that constrain or offer facilities to disabled people, it can produce equipment and machinery, which also has the potential to provide opportunities or create restrictions for disabled people. Technology is rarely 'disability-neutral'. It is often argued that improvements in specific 'disability-related' technology can play a major role in improving the lives of disabled people. These improvements do not always imply more 'advanced' technology, but often technology that is '3A' – appropriate, accessible, and amenable to the needs of disabled people across the world – can improve their lives. For most poor and disabled people, however, appropriate technology is not accessible and what technology is available is not amenable to their needs. This paper is concerned with the relationship between disability, poverty and technology in the developing world.

A CONCEPTUAL APPROACH

It is suggested, firstly, that the concepts of disability, poverty and technology are all best understood in terms of dynamic social processes and this paper sets out an approach to disability, poverty, technology and development based on the social model of disability. It argues that 'disability' is both different from and more comprehensive than 'impairment', and defines disability as the consequence of various forms of social discrimination and exclusion for people with impairments. For this reason, national and international statistics on the prevalence or incidence of physical and/or mental impairment are inadequate as a guide to the prevalence and incidence of disability. Furthermore, such data offer 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 the costs and

benefits of any particular programme. This paper argues the need to formulate an integrated strategy towards disability and development. It recognises the value of programmes like the Knowledge and Research (KAR) programme supported by DFID and recommends the funding of such initiatives in applied or action-research to examine further the relationship in different contexts of disability, poverty and technology.

DISABILITY, POVERTY AND TECHNOLOGY

Although poverty and disability are often conceived as static and specific 'states of being' – a sort of 'negative endowment' - and technology as infrastructure or equipment, they are all better understood as the manifest and specific outcomes of dynamic social processes**.** 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. 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 – as a dependent variable.

The social model offers a powerful framework for understanding the complex issues of disability, poverty and technology. It reveals disability as a crosscutting 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. DFID's statement on Disability, Poverty and Development tends to confuse the two approaches (medical and social), but leans towards the medical model, seeing disability as 'long term impairment, leading to social and economic disadvantages, denial of rights and limited opportunities…' thereby equating impairment and disability and characterising them as independent variables.

Poverty used also to be characterised very much as 'a state of being' requiring intervention and 're-habilitation'; increasingly, however, it is being defined as the consequence of social discrimination and social exclusion. Poverty in this sense needs to be understood as an outcome of social processes, which produce and reproduce it - oppression, subordination, exploitation and discrimination. Poverty is not only a dependent variable, and the consequence of social processes, it also is the root cause of many forms of impairment. But being poor is, even more significantly, a major factor in transforming impairment into disability. Poverty may generate impairment, through malnutrition, disease and inability to gain access to adequate health services; it also excludes those with impairments from many normal every-day activities and thereby increases disability. Disability exacerbates poverty, while having impairment makes being poor more gruelling and inexorable. Poverty, disability and impairment are clearly linked in a deadly mutual embrace.

Technology is best seen as the process of 'the application of knowledge' to find effective solutions to social problems. Technology and its outcomes (which may include buildings, transport systems, assistive equipment, etc.) 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. 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.

THE SOCIAL MODEL IN PRACTICE

The social model has been the foundation for the disability movement, because it offers a true representation 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. 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'.

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.

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.

THE EXTENT OF DISABILITY IN DEVELOPING COUNTRIES

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. Social discrimination based on gender is widespread; so too is discrimination based on other socio-cultural definitions of identity – caste and ethnicity in particular – and on socio-economic

status, or class. These forms of discrimination affect the nature and severity of disability among people with impairments, according to their gender, caste or ethnic group, social class – or indeed age. But relatively little is known in detail about how precisely disability and social discrimination relate to other forms of social division – it may be that poor, low caste women are more severely disabled than wealthy, high caste men with the same physical or mental impairment, but this is not necessarily the case.

The nature of impairment is also poorly understood. Usually taken as a 'given', even in the social model of disability, impairment – like disability – is in fact socially defined and constructed. What is regarded as 'an impairment' in one social context, may not be in another. The registered prevalence of 'learning difficulties', for example, is rapidly rising as hitherto socially unrecognised 'conditions' (e.g., dyslexia) are diagnosed, or as new conditions arise (as in the case of HIV/AIDS, which now falls within the remit of 'disability legislation' in several countries).

Global statistics on impairment (often confused with disability) – because definitions vary, investigations are incomplete and people with impairments are often not recorded or identified as such - are unreliable and based on guesstimates. The figure of 600 million people or 10 per cent of the total population is often cited – but this too is a guess. Across countries, estimates vary from as high as 12-15 per cent (in some developed countries) to as low as 1-2 per cent (in many developing countries). This suggests that data are unreliable and misleading. Furthermore, although some of the reasons for this are, as indicated above, the result of deficiencies in definition or counting, there may be other, more important reasons which remain unclear. The apparently low incidence of impairment in many developing countries may simply indicate that mortality rates are very high among poor people with impairments, and they 'disappear' from the recorded population. It may also indicate generally lower rates of 'recognition' (where physical or mental impairment is more common, the 'threshold' for its definition as 'serious' may be higher). All too little is known.

The new International Classification of Functioning, Disability and Health (ICF) attempts to measure impairment and disability from a perspective that is somewhat closer to the social model (although it still emphasises the capacities and capabilities of the individual rather than the barriers and constraints of his or her social and physical environment) and was adopted by the WHO in May 2001. It will take some time, in any case, to implement. Attempts have been made to address the problem in a more systematic 'objective' fashion. The WHO has compiled figures on Disability Adjusted Life Years (DALYs) by region, to reveal some significant differences in the impact of impairment (and disability) on life expectancy and life expectations, but the measurement itself is based on essentially arbitrary, negative assumptions about the quality of disabled people's lives.

The available global and regional data indicate that malnutrition, resulting from material poverty, is one of the most common causes of impairment and that many kinds of impairment are the result of specific diseases or conditions 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.

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. Both are of major importance, but it is the latter that is crucial for the reduction of 'disability', but is even more difficult to identify and deal with. 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' and 'impairment' to be recognised and understood and the appropriate forms of intervention (whether involving technology or not) devised.

THE VALUE OF INTERVENTIONS

The use of conventional benefit-cost analysis, with its emphasis on direct economic value within a specified (usually limited) time-frame is not really appropriate, as usually applied, in assessing the benefits of interventions designed to address disability issues. Nonetheless, broad social cost-effectiveness must be a consideration in the selection of policies, programmes and projects. 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.

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 has already been recognised as effective in various forms of participatory evaluation, whether it is participatory action-research or participatory learning and action, of so-called poverty-alleviation policies, programmes and projects. 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. A review of experience with disability projects and examination of specific case studies suggests that all projects should be firmly rooted in the expressed needs and demands of disabled people in a specific local social and physical context.

In most developing countries, the national level is where government and international (bilateral and multilateral) agencies are most likely to develop policies, programmes and even projects with respect to disability reduction. But it may be at the sub-national (regional, district and local community) level that such 'higher-level' agencies will need to work together systematically with local NGOs, organisations of disabled people, researchers and others with relevant skills and expertise, to develop appropriate projects, programmes, policies and legislation to reduce disability.

DISABILITY AND DEVELOPMENT: TOWARDS A GLOBAL STRATEGY

Despite the undoubtedly vast number – hundreds of millions at least - 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. There has been growing interest in, and concern about, disability – notably in specific agencies. The World Bank, for example, and USAID; JICA and the Asian Development Bank; NORAD and the other Scandinavian government aid agencies, and some of the international NGOs (like Save the Children) have turned their attention increasingly towards disability issues. Some have even begun to talk about policy to mainstream disability, just as 'gender' has been mainstreamed in recent years. Mainstreaming disability in a major development agency 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 impact of these policies, programmes and projects on disability reduction.

The authors believe that development agencies should increasingly integrate disability within the mainstream of their development policy and practice by adopting a social-model approach and by identifying disability as a major crosscutting issue. This would imply, in effect, adopting a twin-track strategy – already advocated by DFID in its paper on 'Disability, Poverty and Development' - and adopted with respect to gender issues. Several other development agencies have already moved quite a way in this direction. In order to implement such a strategy and policy for 'disability and development', it is essential that all development agency staff recognise the links between reducing disability and other development priorities, such as alleviating poverty. But for this to happen, they have to 'see' disability as a crosscutting development issue. One important way in which this can be facilitated is to introduce appropriate, social-model based disability equality training. Just as 'gender-blindness' has been identified even at the highest levels in international development agencies and NGOs, so too the risk is strong that 'disability blindness' may affect these agencies, unless strong preventive measures are taken.

There is a growing interest in, and concern for, disability issues in development among the major international agencies. Several international NGOs and some organisations specifically concerned with disability and development have already charted the broad direction in which theoretical and practical work should be moving. Greater effort needs to be put into disseminating new information and best practice with regard to disability and development between institutions and agencies. Publications such as Asia Pacific Disability Rehabilitation Journal produced by Action for Disability should be able to play a significant role by publishing ideas, experience and case material, examples of best practice and of innovations which can feed into what needs to be a fuller and more comprehensive international discussion and dissemination process. At the same time, those working in the field of disability and development should be aiming to write for publications in development studies so as to reach a wider and different audience, of development policy-makers, practitioners and professionals. On the other hand, those with experience and expertise in disability and rehabilitation should be equipping themselves with an appreciation and understanding of the latest thinking in development, bringing development and disability studies and practice closer together.

PROPOSALS FOR THE DEVELOPMENT OF DFID'S DISABILITY STRATEGY

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. The establishment and continuation of DFID's Knowledge and Research (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. But while the establishment of the KAR Programme and the production of the strategy paper mentioned above indicate an emerging awareness within the agency 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.

Recent re-structuring of DFID has meant that a certain amount of impetus has been lost as old departments and divisions have been replaced by new teams and focal areas. It is not at all clear where responsibility for disability issues and development 'sit' in the new DFID that is now beginning to emerge from its re-organisation. Perhaps it is a good time to define a new strategy. Such a strategy should be developed in collaboration with other like-minded international agencies seeking to integrate disability work with development priorities, whether these are essentially disability- or development- focused, and with the existing international organisations of disabled people.

The authors suggest that DFID establish a cross-sectoral, cross-thematic Disability and Development task force or team with a clear mandate to mainstream disability and to focus more attention on it as a specific development issue. In the new KAR Programme for 2003-2006 there is a specific 'project' to assist DFID in developing such a focus on disability and development. In terms of defining strategy for DFID, one possibility would be to commission the re-drafting of the short paper on Disability, Poverty and Development, to provide a more substantial and substantive document on which to base policy and practice throughout the organisation. Another would be to produce more focused papers showing how disability would be integrated into the work of specific teams and focus groups.

THE NEED FOR RESEARCH ON DISABILITY AND DEVELOPMENT

One urgent priority is to increase knowledge about existing approaches to disability and development, both in theory and in practice, and to identify 'best practice' as regards disability and development, both in government agencies and in non-government organisations. This should be undertaken through an initial review of research and publications on 'disability and development', which could complement existing reviews of CBR and related programmes.

At the same time, a register or compilation of statements and policies on disability and development by international, bilateral and non-government agencies and organisations would be valuable, as would 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). Healthlink Worldwide under the previous KAR Disability and Healthcare Technology Programme has made a start on this. Thirdly, in the context of a stated concern with respect to technology for disability reduction, an international network of technology providers for disability reduction needs to be compiled.

The authors also argue that it would be useful to undertake a comprehensive study, which would involve a review of literature (and other sources) relating to disability and development, a review and analysis of significant programme or project initiatives (involving research and/or implementation), and a listing and discussion of country-by-country experience with respect to disability and development. This would constitute a fairly substantial project, but could be undertaken on a collaborative basis.

There are several areas in which new research should be carried out. The issue of disability and older people is becoming a matter of major concern in many developing countries as the demographic structure changes. Projects related to this issue, would be a priority. There is evidence to suggest that in developing countries many children with impairments die young or are ignored. We need to know much more about such children and their early lives. Finally, the relationship between disability and poverty requires more systematic investigation on a comparative basis across countries.

CONCLUSION

This paper emphasises the need to recognise the importance of disability as a development issue, as a social issue, and as an issue closely linked to the stated priorities of the major international and bilateral development agencies and NGOs.

Technology generates outcomes and products which could be liberating and empowering for disabled people, but, like both 'disability' and 'poverty', it needs to be seen as essentially a social process, capable of generating negative as well as positive outcomes as far as disabled people are concerned.

More research is needed to identify examples of best practice as regards developing appropriate technology for disabled people. 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.

Disability should be mainstreamed in the policies, programmes, projects and daily practice of development agencies and consideration given to the development of appropriate technologies as one component of a strategy for disability and development.

Development agencies, like DFID, need to recognise the importance of disability at all levels, and develop an appropriate institutional response, including the introduction of disability equality training and 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 should include a section on disability and development, as an integral part of their overall vision for the development of the country concerned; and country level staff should also receive disability equality training.

DFID and other development agencies should promote a twin-track approach to disability, as has been done with gender. All development 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.

*School of Development Studies
University of East Anglia
Norwich NR4 7TJ, UK.
j.d.seddon@uea.ac.uk

ACKNOWLEDGEMENT

CROSS-LINGUISTIC STUDY OF ACQUIRED READING DISORDERS IMPLICATIONS FOR READING MODELS, DISORDERS, ACQUISITION AND TEACHING

Author: Prathibha Karanth

The study of acquired reading disorders has served as a touchstone of research on language and the brain. Researchers believe that an in-depth analysis of reading disorders could lead to comprehensive models of the representation of reading skills and its subcomponents in the human brain. Significantly, in the past decade, there has been an increase in the research on learning to read and write and on the factors affecting reading within broader cross-linguistic and cross-cultural perspectives.

This volume focuses on cross-linguistic studies of the acquired disorders of reading and what they can tell us about the models of reading and the human brain. The author has compiled a source-book on cross-linguistic studies of reading disorders with data from the alphasyllabaries of India, in addition to showing the implications of these findings on the understanding of reading, its acquisition, and the developmental and acquired reading disorders and their management.

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