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CHAPTER 9

Finally Included on the Development Agenda? A review of official disability and development policies

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States, both industrialised and developing, have the responsibility to co-operate in and take measures for the improvement of the living conditions of persons with disabilities in developing countries.

1. Measures to achieve the equalisation of opportunities of persons with disabilities, including refugees with disabilities, should be integrated into general development programmes.
2. Such measures must be integrated into all forms of technical and economic co-operation, bilateral and multilateral, governmental and non-governmental. States should bring up disability issues in discussions on such co-operation with their counterparts.
3. When planning and reviewing programmes of technical and economic co-operation, special attention should be given to the effects of such programmes on the situation of persons with disabilities. It is of the utmost importance that persons with disabilities and their organisations are consulted on any development projects designed for persons with disabilities. They should be directly involved in the development, implementation and evaluation of such projects (*Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. United Nations 1993: Rule 21).

Introduction

In a rather perverse way the promulgation of the *Millennium Development Goals* (World Bank Group website) because they did not specifically

mention disability with respect to the key aim of poverty reduction, may have served as a catalyst, encouraging many people and organisations to affirm or reaffirm the links between disability and poverty. Of course, such concerns, together with the argument that disability is essentially a human rights issue, have been around for a considerable time. These form the bedrock principles of the international disability movement. Furthermore, the adoption by the United Nations of the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (UN 1993) marked an important milestone in the official international recognition of the need to address the social and economic exclusion of disabled people. It is against this background, as well as because of the continued lobbying by the disability movement, that we can address some of the factors which account for why disability has moved up the development agenda.

A prominent example of this was given by James D. Wolfensohn (2002) director of the World Bank:

Addressing disability is a significant part of reducing poverty. Bringing disabled people out of the corners and back alleys of society, and empowering them to thrive in the bustling center of national life, will do much to improve the lives of many from among the poorest of the poor around the world (p. A25).

A year later the European Commission (EC) produced a *Guidance Note on Disability and Development*, in which they stated that:

In the last few decades, disabled people's organisations around the world have promoted a human rights approach and an environmental approach to disability issues. These approaches are both based on a social model of disability...

If the interests of disabled people are not recognised then the key goal of poverty reduction in developing countries will not be achieved. Nor will the human rights of people with disabilities or their participation in society be promoted. If sustainable poverty reduction is to be achieved, disability needs to be addressed by sensitising people active in development work funded by the EU to these issues (European Commission 2003: 2).

These statements are broadly representative of declarations from many other major international and national bodies concerned with development. However, despite this, in terms of having any impact on the lives of disabled people in developing countries, it is more important to consider if these pronouncements, or indeed the basic tenets of the

Standard Rules, are reflected in the official policies (defined as norms expected to be incorporated into an agency's strategy and practice) adopted by the leading development agencies. Of course, determining this is only a first step because policies are often either not put into practice or if they are their implementation is ineffective. Practice is touched on in this chapter mainly for illustrative purposes and to draw provisional conclusions about the impact of policy. To research this question in the depth it requires would be a formidable undertaking. Our primary focus here is on official policies, as this offers a first step to understanding how, and in some cases if, the relationship between disability and development is understood by the principal national and international aid agencies. It must also be said that official policy is often difficult to capture as it is constantly changing.

Finding out precisely what official policies were was difficult. Furthermore, while some organisations had disability policies, it was clear on further investigation that these had either never been implemented or had evaporated on their way down the line to the project level. Another difficulty was that many agencies have produced documents on disability and development, the status of which was unclear. For example, in 2000 the Department for International Development (DfID) published an issues paper, *Disability, Poverty and Development*. This was not a policy statement, never had any impact on the organisation, and indeed seems to have become better known outside than inside the DfID (Thomas 2004). However, in their 2003 report, *Label Us Able*, produced by STAKES for the Finnish Ministry of Foreign Affairs, it is stated that that the DfID's issue paper has been 'official policy since 1999' (p.22) Therefore, the existence of documents referred to as policies are not necessarily evidence of official policy, let alone action on disability and development. (For more detailed information on these development agency disability policies see paper by Albert at: <http://www.disabilitykar.net/resources/karprogreports.html>.)

Defining Disability

A clear definition of disability would seem to be central to designing a disability policy or strategy. If disability is seen essentially as a health issue the solutions will be quite different from an understanding of disability that highlights human rights, discrimination and exclusion. It was, therefore, quite surprising to find so little serious attention paid to this question. When an attempt was made at a definition, in most instances, as in the case of the DfID outline below, it represented a compromise between different, and quite opposed, ways of understanding disability. In most cases even a

composite definition was not given and it was necessary to impute a working concept of disability.

The traditional understanding of disability is that it is what is 'wrong' with someone. According to this formulation disability equals impairment, being unable to walk, being deaf or blind, having a mental disorder, or a condition such as Down's syndrome. While those who adopt this view (the individual or medical model of disability) may agree that there are unfortunate social consequences which arise from being disabled, the essential nature of the problem is medical, begins with individual deficit and the primary solutions are, therefore, cure, care and/or rehabilitation.

Since the 1970s, the international disabled people's movement has challenged this understanding, arguing that it is not physical or mental conditions which are disabling but social, attitudinal and physical barriers preventing equal participation in community life. Disability, according to this conception (generally referred to as the social model of disability), is the result of discrimination and social exclusion. It is a human rights issue which demands a socio-political rather than a health-based focus (Albert et al. 2002), although this has been disputed by Vic Finkelstein (2001), one of the early pioneers of the social barriers approach.

Only the European Union Guidance Note, quoted above, mentions the social model of disability. In all the other official documents either a medical model may be assumed or a definition is adopted which tries to combine both models. The clearest example of the latter is found in Dfid's (2000: 8) issues paper which considers both models and then decides it is preferable to go for 'an integrated approach using best practice in both social and medical terms'. On the main web page of their disability website, *World Bank* observes:

Defining what is meant by disability is sometimes a complex process, as disability is more than a description of a specific health issue; rather it is affected by people's cultures, social institutions, and physical environments. The current international guide is the World Health Organization's discussion and classification within ICF: *International Classification of Functioning, Disability and Health*. ICF presents a framework which encompasses the complex multifaceted interaction between health conditions and personal and environmental factors that determine the extent of disablement in any given situation.

The Asian Development Bank (ADB 1999) adopted a similar position, opting for the World Health Organization (WHO 1980) definition. More recently, in a draft of a handbook addressing disability and poverty they seem to sign up for the revised ICF. It is perhaps to be expected that these major international bodies choose to follow the definitional guidelines established by such an influential sister organization.

The new ICF seems set to become the gold standard for defining disability. However, even though disability ('disablement' is the word used in the ICF) is now seen as arising from the negative impact of the environment in its broadest sense, the minute classifications of health and functioning remain central. Many critics have argued that the ICF represents medical model thinking clothed in watered down social model language (Bury 2000; Pfeiffer 2000; Miles 2001). As with the DfID definition, it starts with the individual, rather than society, and tries to find a compromise between the two ways of understanding disability:

Whilst the ICF asserts that individuals are but one element in the analysis of disability, the 'biopsychosocial' approach is not that far removed from its forerunner in that it retains the individual as the starting point for the analysis of 'bodily function and activity'. The concept of participation is included but underdeveloped in the scheme and is still linked to individual circumstances rather than tied firmly to social and political inclusion (Barnes 2003: 9).

Of course, ICF comes from the WHO, so it is hardly a surprise that health is the primary concern. But the extension of this concern to a conception of disability as a socio-political construct may not be particularly helpful for the practical business of designing development policies and practices which break with traditional medical assumptions, seek to promote human rights and bring disabled people into the mainstream of society.

Rachel Hurst, an experienced disability activist who took part in redrafting the ICIDH, has no illusions about the difficult compromises that had to be made, but claims:

ICIDH2, with all its many faults and its misuse of disability language, can, I believe, now be used as an international example of how the environmental impacts are the key to understanding the nature of disability/disablement and how solutions must come through social change (Hurst 2000: 1086).

Whatever the possible benefits with respect to planning for health provision and whatever the ICF says about the need to see disability in terms of environmental factors, because of its genesis in the medical world, its emphasis on classification of function and its staggering complexity, it is doubtful whether it will overturn deeply-held medical assumptions about the nature of disability. Because such assumptions tend to inform action, there is the strong possibility that, no matter what is said, in practice international development agencies will default at all levels to a health-centred understanding of disability. The only way this will be avoided is by an ongoing, critical awareness of the contradictions inherent in the ICF together with a vigorous commitment to human rights supported by clear practical guidance for implementation.

Approaches adopted towards disability issues

Despite a lack of a clear definition, the use of the ICF or a medical model understanding of disability, in the cases where there have been policy statements, the majority advocate a human rights approach. This might indicate that how disability is understood is of little concrete importance, but the overall failure to implement human rights policies and/or mainstream disability in development may suggest just the opposite. This is not, however, to argue that adopting the social model will in itself be the key to more effective engagement with disability issues.

The increasing focus on a human rights agenda follows decades of lobbying by disabled people, the lead given by the United Nations, particularly since the promulgation of the *Standard Rules* in 1993, and the more recent negotiations on an *International Convention on the Promotion of the Rights and Dignity of Persons with Disabilities* (UN ESCAPP/CDPF 2003). It is, therefore, to be expected that various UN agencies have a stated commitment to a human rights approach. Such a commitment is also prominent in the policy statements of Scandinavian countries, suggesting at least an implicit acceptance of some key arguments derived from the social model of disability.

The Scandinavian DPOs and their countries have played a leading role in putting human rights at the heart of disability and development. In 1991 the Nordic DPOs agreed to lobby their governments for increased action on disability and development. In 1996 the Finnish government made a formal Decision-in-Principle to include 'the status of disabled people as a concern in the context of poverty reduction and human rights' (STAKES 2003: 28). Four years later in Copenhagen, the Nordic ministers for development co-operation declared:

Recognise and promote the UN *Standard Rules* as guidelines for all bilateral and multilateral development work and to assure, that special measures are taken to create accessibility and participation in development society for persons with disabilities in order to strengthen their possibilities to exercise their human rights (Copenhagen Conference 2000: 5).

While this commitment continues to be reflected in some of the Nordic countries' disability policies, there has been criticism that with the exception of Norway, overall there has been a failure to establish national strategies for the inclusion of the disability dimension in development. Indeed, in Denmark there has been a decision not to make mainstreaming of disability a priority (Ulland 2003). Even in those countries with positive sounding policies what the human rights approach means in practice remains at best ambiguous.

Elsewhere, although a number of other European countries have indicated that they are considering disability and development policies, only Italy has one. The Italian guidelines are comprehensive, if at times somewhat eclectic. They begin with strong statements on the centrality of human rights and then detail how disability needs to be twin tracked - both mainstreamed into overall policy and supported through disability specific projects.

The USAID policy seems set more in the traditional anti-discrimination mode which characterises the Americans with Disabilities Act and other civil rights legislation in the US. The 1997 policy document states:

To avoid discrimination against people with disabilities in programs which USAID funds and to stimulate an engagement of host country counterparts, governments, implementing organizations and other donors in promoting a climate of non-discrimination against and equal opportunity for people with disabilities (USAID 1997: unpagged).

The definition of disability is, however, strictly medical.

For purposes of this policy, a disability is defined as a physical or mental impairment that affects a major life function, consistent with the definition of the Rehabilitation Act (USAID 1997: unpagged).

This is similar to the UK Disability Discrimination Act 1995, which defines disability medically, while setting out social-model-like provisions about non-discrimination.

Policies into Practice

Good disability policies are important, but little more than empty rhetoric unless they are effectively implemented. Unfortunately, with few exceptions, this is generally the case. One of the clearest examples is that of USAID which since 1996 has been trying to develop a more inclusive approach to disability issues. In its 1998 report on policy implementation it explained the key reasons behind the new policy initiative:

It was recognized that the needs of PWDs (*people with disabilities*) 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 (USAID 1998: unpagged).

To carry out this programme they established a central disability team and moved to ensure that each USAID mission devised a disability plan and established links with local DPOs. The policy was backed up by plans for disability equality training for the organisation, although no extra funding was appropriated. While all this sounded promising, by 2000, and the second implementation report, although some positive results were evident, the overall evaluation was notably candid and downbeat:

Efforts at promoting the USAID Disability Policy have been disjointed and minimally effective. Strong words at the highest levels dissipate rapidly. Opportunities for personal contact with PWDs, while fruitful, have not been deemed a priority, while a reward structure does not exist to promote adherence to this policy. While the Disability Policy and the World Program of Action call for inclusion rather than distinct disability programming, feedback to Team members strongly suggests that in this time of conflicting priorities, specific funding must be attached to this target (USAID 2000: unpagged).

A third report in 2002 was considerably more optimistic (USAID 2003). In that year, disability reports were received by 48 USAID missions, as opposed to only 28 two years before. While just 11 said they had drawn up specific disability plans, 34 reported they were working actively with local disability organizations. A most positive feature of the report was that democracy and governance accounted for the largest single number of

projects (19). Nonetheless, important problems remain. Specific disability projects, many in traditional social welfare areas, rather than mainstreaming, seem to account for most missions' efforts. Unlike the disability movements in the Scandinavian countries, disabled people's organizations in the USA have had little input into USAID policy. A report from the National Council on Disability in the following year was even more critical, noting that besides being underfunded:

The USAID Disability Policy includes no specific objectives or timetables, creates no new initiatives to reach out to people with disabilities, and does not require U.S. Missions abroad to change their practices (National Council on Disability 2003).

Another national agency which has carried out an evaluation is the Finnish Ministry of Foreign Affairs. In absolute terms their spending on disability is small averaging (1991-2001) just 6.2 million euros, although this did represent a respectable 5 per cent of their aid budget. As with other Scandinavian countries their disability and development policies have in general been advanced compared with the rest of the world. Nonetheless, the report found that:

Most of the assistance via NGOs has been effective and has made an impact on the planned target groups, for example, training of the deaf and blind in specialised institutions has received a lot of funding. However, the impact on some individuals has been limited and it has had less influence on communities and countries. This is because most of the assistance has been disability-specific (targeted at the people with disabilities) and has been based on the dominant social welfare approach (STAKES 2003: 80).

There were also criticisms that disability had not been mainstreamed into development, that there had not been enough attention paid to adjusting policy in line with the shift from a social welfare to a human rights approach and that the overall policy had to be overhauled to take into account the new international aid instruments for the poorest countries, such as SWAps (Sector Wide Approaches) and PRSPs (Poverty Reduction Strategy Papers).

Norway too has an excellent disability in development policy and in 2002 produced a detailed guideline for its implementation (NORAD 2002), but two years later a commissioned study concluded that:

A main finding of the review is that the guidelines were not known among the target group; not by the Norwegian

Embassies nor by Norwegian NGOs or international NGOs that receive most support from NORAD/MFA (Ministry of Foreign Affairs) (Hertzberg and Ingstad 2004: 9).

An important issue raised by all three examples, and one which seems to apply to almost every agency, is the failure, despite stated intentions in some cases, to mainstream disability into development policy. Although far more detailed research would be needed to confirm this, if the Finnish, Norwegian and US experiences are even close to representative (Denmark 2000), in the vast majority of cases when there is a disability focus it continues to be on the traditional areas of health or special education, relatively small scale projects funded through NGOs, and almost all undertaken with a social-welfare mindset (even if human rights language is used) rather than a meaningful human rights framework. If true, this means that, with very notable exceptions - mainly capacity-building projects run by NGOs - disability issues remain trapped within a special-needs ghetto, the language of human rights remains empty rhetoric and the needs of disabled people for equality, dignity, social inclusion and poverty alleviation remain unfulfilled.

Such a pessimistic analysis seems more likely if we consider what has happened with PRSPs, which since 1999 have become the main multilateral instruments (mandated by the World Bank and IMF) for providing debt relief and, therefore, development aid, to the poorest countries. According to an International Labour Organisation (ILO) Report which reviewed 29 Interim PRSPs for Africa:

... apart from some notable exceptions - persons with disabilities have again been either 'forgotten' or treated in a way that does not correspond to their aspirations to socio-economic integration. Up to now, persons with disabilities have not been involved in an opportunity to be included in the most important poverty reduction initiative of recent years (ILO 2002: unpagged).

A sampling of the World Bank website confirms that in almost all PRSPs there is either no mention of disability, if it is mentioned the reference is to 'the disabled' within a list of vulnerable groups and/or to either social welfare or health. Perhaps this should not come as a surprise when overall PRSP implementation has been seriously flawed, particularly in terms of human rights (UN 2001), and poverty reduction has been minimal (Oxfam 2004). Furthermore, gender, a much more prominent cross-cutting issue than disability, has also not been well served by PRSPs:

On gender equity, almost all PRSPs have been very weak, with minimal attention paid to the issue. World Bank and IMF Joint Staff Assessments of PRSPs singularly fail to address gender equity. Oxfam and its partners believe that gendered poverty strategies are the only ones that will actually succeed in reducing poverty, and that the IMF and World Bank could do much more to ensure that the next round of PRSPs routinely and comprehensively addresses the issue (Oxfam 2004: unpagged).

The failings of PRSPs to include disability are echoed in a 2002 baseline assessment of the World Bank's activities relating to disability which concluded that:

Based on the sampling from this study, few of the current activities of the World Bank include disability in any meaningful way (Stienstra et al. 2002: unpagged).

When they went on to look at five key criteria for assessing inclusion - lending, knowledge, mandate, resources and accountability, all were found significantly deficient. Their comments on lending are particularly interesting. They observe:

According to the survey results of Bank projects, a majority of respondents thought their projects addressed disability. However, almost all responses suggested that disabled people might benefit, rather than that they were included explicitly. Only one project had specific disability components and none mainstreamed disability into the project (Stienstra et. al. 2002: unpagged).

It is probably too early to judge the World Bank's efforts, as these were given a new impetus only in 2002 by the appointment of Judith Heumann as their first Adviser on Disability and Development. In the intervening period (to 2004) there have been lots of upbeat statements, but on the ground little seems to have changed. For example, at a recent meeting hosted by the World Bank, 'International Dialogue on Disability and Development', in Helsinki the participants were extremely critical of the lack of action and concluded:

that the disability and development landscape has been characterized by small, fragmented, unsustainable projects; a disconnect between disability and mainstream development efforts; a 'flavor of the month' approach to country focus; preoccupation with prevention, to the exclusion of rehabilitation and inclusion; 'exclusion by design' in mainstream projects; and poor coordination, evaluation and knowledge-sharing (Disability World 2003: unpagged).

The Bank has launched a consultation process to develop a Global Partnership for Disability and Development, but while this is a positive step, the preamble to the draft 'Concept Paper' shows just how far there is to go before any meaningful changes can be expected.

Poverty alleviation in developing countries and genuine progress toward achievement of the Millennium Development Goals requires that disabled people be explicitly taken into account in national and international economic development efforts. The social and environmental obstacles that marginalize and impoverish disabled people cannot be dissolved by any one kind of entity or organization, but only through the collaborative efforts of diverse stakeholders, including governments of developing and developed countries, multilateral development agencies, members of the United Nations family of agencies, foundations, national and international NGOs, and the private sector.

Yet the idea of mainstreaming disability into the economic development agenda is a novel concept to many foreign assistance providers, developing country governments, and even NGOs. There is sometimes a disconnection between the people who are knowledgeable about international economic development and foreign assistance on the one hand and disability on the other (World Bank 2004: unpagged).

Conclusion

Is disability really on the official development agenda? If by this we mean are some of the main players talking about the issues, then the answers would be 'some of them' and 'sort of'. If, however, we are concerned about real changes being put in motion, even with a small percentage of the degree of the commitment given to gender, another major cross-cutting issue in development, the most optimistic answer would be 'not yet'. In fact, disability still does not figure as an official cross-cutting issue for any national development agency (Yeo and Moore 2003). The experience of gender indicates how far there is to go, for despite the strong policy commitment of almost all development agencies on gender, a great deal remains to be done and this commitment has not been followed through in the poorest countries with respect to the new international aid instruments.

While the World Bank, major UN-related agencies, the US, and most Scandinavian countries have made positive statements on disability, up to now these remain little more than statements. In most cases their policies have not been implemented and it seems they are struggling to find practical means to deliver their promises. Most of the evidence and comments, even from major agencies like the World Bank, seem to confirm this. The European Union has promulgated excellent guidelines for disability and development, but most of the major European countries have not even progressed to the stage of formulating policies.

Of course, there have been many disability-focused development projects, and some of these have undoubtedly delivered positive results for disabled people. The reports from the USAID missions seem to be particularly encouraging in this regard. However, reports from the USA and the UK (Thomas 2004) and from Finland (STAKES 2003) suggest that most of these projects remain locked within a traditional social welfare paradigm with limited value for mainstreaming disability in development and delivering a wider human rights agenda. In cases where the disability agenda is farmed out to NGOs, as in the UK, despite the excellent results achieved (Action on Disability and Development 2002), this may have simply confirmed the 'special' nature of disability and to that extent made effective mainstreaming within the DfID more problematic.

What is called for from international aid agencies, besides a far stronger and far clearer commitment, is a genuine understanding that disability is a social issue which cannot be addressed without bringing disabled people's organisations, both in the South and in the North, into the heart of the process, as has been done in the latter case in Finland, Norway and Sweden. There has been a strong emphasis on inclusion of disabled people in the South in USAID policy where:

it is clear that "best practice" occurs when USAID and disability voices are combined in developing solutions (USAID 2003: unpagged).

Disability needs to be mainstreamed, promoted explicitly and officially as a cross-cutting issue as has gender. In fact, as a start it would be useful to consider disability within the same general parameters that have been set out for gender (Derbyshire 2002). Above all, we must not let good intentions or fine sounding declarations about human rights substitute for action which addresses the social exclusion, grinding poverty and human rights' abuses which continues to blight the lives of disabled people throughout the world.

In summary, development agencies need the following:

- a precise, high profile and robust policy on disability;
- a time-bound strategy for its implementation specifying ‘who, what, when and how’;
- tracking indicators and the linking of disability policy to other monitoring and evaluation procedures;
- a clearer understanding of the social model of disability and how this relates to effective human rights policy and practice;
- a stronger commitment to involve DPOs from both North and South at every level of development work;
- the mainstreaming of disability explicitly as a cross-cutting issue on a par with gender;
- to learn disability-relevant lessons from their experience of work on gender.

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