One of the most significant contributions of the Disability KaR centres on the research process itself and the attempt to offer a radical method of transforming the social relations of research production (Oliver 1992). The need to do this is because of the failure of international disability research in general and disability and development co-operation in particular to rise to the challenge posed by the social model of disability (see Chapter 3).

After a consideration of the way in which most research is developed and carried out, we offer an alternative method, although interestingly, one that conforms to both DFID’s human rights approach to development and its Central Research Department’s emphasis on research being participatory, relevant and demand led.

The traditional research model
Despite the rhetoric of the rights-based approach and the social model, most understanding of disability is still rooted in a medical or charity-model paradigm. For example, in November 2004 the Disability and Development Team at the World Bank (WB) held a meeting bringing together bank staff and outside experts on economic development to help devise a research programme on disability and poverty (Metts 2004). Reviewing notes of the meeting, there is no doubt that the discussions were informative and have given the WB a sound platform for moving ahead. However, one key element which seems to have been missing from these deliberations is the representative voices of disabled people from the South - the objects of the gathering’s concern.

What was happening here, by a group with a disability consciousness higher than most and one that seems meticulously inclusive in all other respects, is a replicating of the daily experience of most disabled people – other people making decisions in their best interests. In this kind of organised ‘professional’ discourse, which characterises most of disability research, academics, INGOs
and the entire development industry assume that disabled people are objects of concern, not initiators of such action on their own behalf. This is not to say that either the Disability and Development Team or the participants were doing anything ‘wrong’ or that they don’t care about the lives of poor disabled people in the developing world. Far from it. It is just that they are modelling their approach to research in a way which mirrors and is likely to perpetuate the very thing they want to challenge - the social exclusion of disabled people.

Critiquing the traditional model
Of course, critiques of this kind of top-down research paradigm are well known, most prominently in the works of Paulo Freire (Freire 1972) and Robert Chambers (Chambers 1983). These are generally associated with research in the field, especially Chambers’ PLA (Participatory Learning Approaches) and PRA (Participatory Rural Appraisal). However, Sue Stubbs points out (Stubbs 1999) that ‘..the broader philosophical and ethical issues raised in the methodology…’ can be transferred to a wider research arena. She continues, ‘PRA proposes a methodology which builds on the notion that local people are capable of sharing, enhancing and analysing their own knowledge in order to plan, act and promote their own development.’ Further to this, Rebecca Yeo has commented (Yeo 2001),

Traditional research often involves wealthy non-disabled outsiders questioning people about their lives. This is not a reliable way of getting information where there are big power differences and where questioners are not trusted friends. To get consent is not sufficient, as few people in situations of poverty and exclusion will refuse to be questioned by those with more power and authority. It is therefore essential that disabled people are fully involved in future research, including setting the agenda.

The main counterargument to this type of criticism is generally twofold. You don’t expect other groups of people to tell statisticians, economists or other professionals such as doctors or architects how to do their jobs. Why should disabled people be privileged in this respect? Also DPOs are not likely to have the necessary expertise. In the first place, perhaps all professionals would do a better job if they listened more to those who they are supposed to serve. Disabled people would definitely put doctors and architects at the front of that particular queue. Secondly, with respect to research which concerns itself with
the lives of disabled people, it is precisely these people who are the experts. If professional assistance is needed this should be put at their disposal to achieve their agenda, not the other way around. In the words of David Werner, ‘…it is time for non-disabled professionals to recognise the right of disabled persons to self control, and therefore to gracefully step to one side, into a role where they, as professionals, are no longer on top but rather on tap’ (Werner n.d.). If disabled people are not at the very least in the room when decisions are being made about them and able to question and actively participate, then those decisions are likely to be that much poorer for their absence.

Another point frequently made is that disabled people actually are included as active participants in disability research. Increasingly, funders are demanding this as a condition for awarding disability project grants. In most cases what this has meant is that INGOs and academics, who have the resources and knowledge to bid for such grants, develop research projects and then go hunting for southern DPOs willing to become ‘partners’ (see below). This downstream involvement generally results in tokenism, with the research agenda being preset, the unequal power relationship between researcher and researched not being challenged and real control remaining in the hands of the intermediary organisation and/or professionals.

The foregoing arguments will be familiar to anyone who has followed the long-running debates about participatory and emancipatory research. The former is broadly about research subjects taking an active part in the process, the latter about them being able to control the process from beginning to end, thereby grounding the research in their daily experience and making it more relevant to fostering positive and sustainable change.

Emancipatory research
For disability, emancipatory research begins by conceptualising disability in social-model terms as a form of oppression, that is people with impairments having to face a complex panoply of discrimination and social exclusion. Because this involves socially imbedded discrimination and derived notions of power inequality, disability is always a political issue. Most importantly, the object of emancipatory research is to transform and emancipate, not to engage in research for its own sake. As Colin Barnes points out:

In essence, emancipatory disability research is about the empowerment of disabled people through the transformation of the material
and social relations of research production. In contrast to traditional investigative approaches, the emancipatory disability research agenda warrants the generation and production of meaningful and accessible knowledge about the various structures—economic, political, cultural and environmental—that created and sustain the multiple deprivations encountered by the overwhelming majority of disabled people and their families. The integrating theme running through social model thinking and emancipatory disability research is its transformative aim: namely, barrier removal and the promotion of disabled people’s individual and collective empowerment. From this perspective the role of the researcher is to help facilitate these goals through the research process. (Barnes 2003)

In a recent report funded by the Joseph Rowntree Foundation, *Research as empowerment?* (Hanley 2005), it was claimed that in most research with oppressed groups, because of the unequal power relationship as between researchers and researched, ‘…the aims or methods employed in research projects did not capture or reflect the lived experience of those it was notionally intended to benefit.’ From this study a number of basic standards of good practice are put forward (see box). We feel these offer an excellent starting point for thinking about how to structure the research process so it meets the aspirations of disabled people in the South.

These aspirations came out clearly in interviews and in the response to questionnaires from all the southern DPOs (Albert, Dube, et. al. 2005). As shown below, a survey of 10 DPOs in Zimbabwe found that there was an overwhelming feeling that disabled people should have the leading role in research. In Zambia similar sentiments were expressed. The Zambia National Federation Of the Blind said that, ‘…disabled people should be part of the implementers of the research as this is about them and so we feel they are the best people to spell out what they want to be done.’ This was echoed in replies from seven other DPOs. The country’s main umbrella organisation, Zambia Federation of the Disabled (ZAFOD), observed, in line with David Werner’s admonition about the appropriate roles of professionals and disabled people, that ‘DPOs should play a leading role in this research process with consultancy services from research institutions.’
Good Practice in Emancipatory Research

• Users are involved from start to finish, and there is a commitment to act on the results of the research.
• Funders are equally committed to resourcing and prioritising user involvement.
• Training and support are available for users and researchers.
• A commitment to make the research accessible to those whose lives it reflects. The project does not simply end when the research is complete – there is a commitment to action as a result of the research.
• Researchers are committed to sharing power and control with service users.

(Hanley 2005)

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<th>Zimbabwe DPOs role in the research process</th>
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In Bangladesh a workshop was organised by the National Grass-root Disabled Federation of Bangladesh together with Action on Disability and Development (ADD) to discuss research priorities. They agreed that although capacity building and support was needed, disabled people should conduct their own research because they, ‘Provide realistic information from the society and life experience, are able to find out their own problems, they know better about themselves than others…’ and are well placed ‘…to identify ways to resolve problems.’

In Afghanistan a workshop of leaders from 12 DPOs thought that they should participate at every stage of research and that ‘DPOs have experience and different ideas and views that are very important in a research process and … can provide good data from their own life experience to conduct any research
Many foreign agencies and some government ministries expressed roughly similar views, although it was interesting that UNICEF and Handicap International (HI) were considerably more traditional in their approach. The representative of the former said that ‘DPOs should be targeted for consultation in the research work to get information from them. They can work in data collection and data processing in the research process.’ The country director of HI remarked ‘It is very important to listen to the DPOs as they have accurate and genuine information. DPOs will be the part of whole research process.’ Clearly such approaches are more about participation, whereas here, as elsewhere, DPOs are asking for a leading role in the research process.

In this regard, it is disheartening to see that the World Bank, which should be setting the standard of best practice, is backing this kind of top-down, paternalistic approach. In a message on the Global Partnership on Disability and Development email list (June 9, 2005), in what appears to be ‘business-as-usual’, the WB are funding Handicap International and the Christian Blind Mission International (CBMI), another large INGO, to ‘…develop a framework for inclusion of disability in PRSPs.’ They will, of course, ‘Involve persons with disabilities in the process to help ensure that the materials correctly address disability issues’, but this is very much downstream involvement, with DPOs ‘participating’ (and they would have to, wouldn’t they?) rather than initiating or leading the process. This is, strictly speaking, a project more than research per se, but the same issues of control apply. Also, we are not decrying the involvement of such INGOs, only the dominant position of power and control they traditionally assume. It would seem that in this case the professionals are very much on top with disabled people being, as usual, on tap.

The emancipatory research process outlined above is consistent with the demands from disabled people and others in the South as well as DFIDs Central Research Department’s desire ‘…to promote the influence of poor people and developing country institutions as potential users of research – raising the ‘demand-pull’ for research, so that it is more relevant.’ and to engage ‘…users in the design, implementation and analysis of research.’ (DFID 2004) Such a research structure is also in line with DFID’s human rights approach to development. For example, in a DFID leaflet on human rights published in 2002 (DFID 2002), it was observed that, participation was one of the cross cutting principles upon which a human rights strategy was built. This meant, among other things ‘..enabling people to realise their rights to participate in, and access information relating to, the decision-making processes which affect their lives.’ It was
also pointed out that ‘International Development Targets can only be achieved through the engagement of poor people in the development processes which affect their lives. The human rights approach to development means empowering people to make their own decisions, rather than being the passive objects of choices made on their behalf.’ Disabled people and their families make up a large and disproportionate share of the poor in the developing world, and as the previous president of the WB has said on numerous occasions, without including them in the development agenda the MDGs will not be achieved.

Emancipatory research and the Disability KaR
The Disability KaR is an interesting case study as well as an example of the exclusion faced by disabled people and researchers. The project began with only one disabled person as a research advisor. For the first year of its two-year life, disabled people were marginalised in and peripheral to decision making and programme work. What was initially seen by the disability movement as an opportunity to develop some serious emancipatory research around disability and development, was never realised. At best disabled people were invited to ‘participate’ in non-disabled researchers’ agendas. If any critical comments were raised by the disabled adviser on plans, which were generally made without consultation, these were met with defensiveness or hostility. A view that non-disabled ‘disability professionals’ expressed on more than one occasion was that disabled people in the North were seen to be a problem for and by disabled people in the South. Therefore, the same professionals needed to lead and/or mediate programmes. This was the justification for the virtual exclusion of disabled people from programme and decision making processes.

The problems are outlined above to show that programme was operating in a non-emancipatory fashion. It is, however, important to state that some of the non-disabled people involved in the programme had their own criticisms of the approach taken and engaged in a open, critical dialogue with the disability movement. This resulted in some very powerful alliances being forged and was helpful in re-focussing and re-prioritising the programme.

When the original programme director resigned it was possible to open the programme up to disabled people in the South and the North. As well as being conscious of the power relations between disabled and non-disabled researchers it was necessary to address questions of colonialism and ensure the programme did not recreate unequal and discriminatory practices between disabled people internationally. Because the focus of the research is on disability and poverty
in the South, it was necessary to develop transparent and open arrangements for collaborations applying the principles of ‘Nothing About Us Without Us’ to North-South, South-North relationships. As far as possible it was also an aim to involve disabled people as active subjects/participants in each stage of the research.

A number of things were put in place to get the Disability KaR back on track. It became possible to insert the social model as the driving approach to guide the programme. In research terms this meant making the emancipatory approach live through all the processes in the programme. This was achieved by adding additional stages to the research process. The first stage was to engage disabled people globally in deciding WHAT should be researched. This was done by initiating a consultation with disabled people in the South, both at a workshop during the Malawi Roundtable (an event organised by Healthlink International in November 2004) and with representatives of the disability movement in the North and the South through a tele-conference. The agenda setting determined the priorities for both the policy and thematic research programmes, both of which form the basis for this collection.

Once the main research themes had been agreed, the second stage was about including disabled people in a process of deciding HOW these themes should be researched and WHO should do it. This led to a research prospectus built around eight themes and priorities together with a transparent set of criteria upon which the research proposals would be judged. These were around, among other things, the involvement of disabled people as researchers, collaborations between researchers North/South and South/North and the role of disabled people in the research process. These criteria were given points against which proposals would be scored similar to what would be done at an equal-opportunity interview or in a contract compliance process:

- does the outlined method represent meaningful and genuine consultation with disabled people in the South? (10 points);
- does the outlined method allow for consultation/involvement with a wide range of disabled people, including disabled people’s organisations, disabled women and people with different impairments? (10 points);
- does the research team include disabled researchers? (10 points);
- does the applicant provide evidence of capacity/track record in work of this nature? (5 points);
- does the applicant demonstrate understanding of the social model of dis-
ability? (5 points);
- does the applicant have experience of mainstreaming from other sectors? (2 points); and
- does the applicant outline a range of empowering and/or emancipatory research methods and have experience of using them? (5 points).

(Disability KaR Research prospectus 2004)

The research commissioning process then proceeded with proposals being judged on best quality for each theme and meeting the criteria for disabled people’s involvement. Out of the eight themes, seven research projects were commissioned from 24 proposals. This process produced a number of high quality submissions. It also created an exciting range of collaborations between disabled researchers, disability activists, DPO’s and their non-disabled allies on three continents.

When Mark took over as programme director, the KaR had less than a year to run. Because of the shortage of time the research projects had to be completed in 6 months. Before they were completed the research projects were presented to the Programme Advisory Group (PMG). The Research Gap Analysis, the only theme proposed by DFID, was used to inform the way forward for disability research for DFID’s Central Research Department.

The final stage of the process was to invite research groups to propose methods of dissemination. This resulted in a wide range of user-led activities and events including; a workshop in Malawi for the disability movement in Southern Africa, organised by SAFOD and FEDOMA on mainstreaming disability in development co-operation, a conference (‘From Policy To Practice’) for national and regional government in South Africa, focussing on implementing disability policy; and a workshop in Norway for Scandinavian DPOs and government agencies to discuss the challenges and opportunities of mainstreaming disability brought out in the research.

Emancipatory research was the preferred option because it offers the most appropriate methodology for understanding the socio-political process of disablement – how people with impairments are disabled by the complex interaction of negative assumptions and attitudes about them and towards them (internalised by many disabled people themselves) and a plethora of discriminatory actions that lead to environmental, institutional and social exclusion. The Disability KaR research has demonstrated that you get better results if disabled
people are in the lead or in leading roles, if necessary alongside non-disabled researchers who can act as allies. This works as long as the latter are On Tap Not On Top. It also creates sustainability, as the recommendations have a much better chance of being carried forward and implemented by disabled people and DPOs because they matter to them and because they own them. This is where the role of disability researcher and activist overlap in a positive way. The transformational power of the social action/emancipatory approach is that it understands that an informed and evidenced-based process of social change must be an integral part of the research process.

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