Disability KaR
Knowledge and Research

Research Gap Analysis Report

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ODG
DEV

Contents

List of Abbreviations

ADD	Action on Disability and Development
CAS	Country Assistance Strategies
DFID	Department for International Development
DPO	Disabled people's organisation
DPSA	Disabled People South Africa
FEDOMA	Federation of Disability Organisations of Malawi
FFO	Norwegian Federation of People with Disabilities
FODSWA	Federation of Disability of Swaziland
HIPCs	Heavily Indebted Poor Countries
HIV/AIDS	Human Immuno-deficiency Virus/Acquired Immune Deficiency Syndrome
ICF	International Classification of Functioning, Disability and Health
ILO	International Labor Organization
INGOs	International non-governmental organisations
KaR	Knowledge and Research Programme
LSMS	Living Standards Measurement Surveys
MDGs	Millennium Development Goals
NCDZIM	National Council of Disability of Zimbabwe
NFPDN	National Federation of People with Disabilities Namibia
NGO	Non-governmental organization
NUDIPU	National Union of Disabled People of Uganda
ONS UK	Office of National Statistics
PEAP	Poverty Eradication Action Plan
PRSCs	Poverty Reduction Support Credits
PRSP	Poverty Reduction Strategy Paper
PSA	Public Service Agreement (DFID's)
SAFOD	Southern African Federation of the Disabled
SDAs	Social Development Advisors (DFID)
TOR	Terms of Reference
USAID	United States Agency for International Development
UN	United Nations
UNICEF	United Nations Children's Fund
ZAFOD	Zambian Federation of Disability

Acknowledgements

Executive Summary

Aim of the project

The principle aim of the project is to assess the gaps in research with respect to disability and development, review current work being carried out in relation to these gaps, recommend the most fruitful areas for DFID's future research agenda on disability and develop ideas on how the research process should be structured.

Expected outcomes

1.   To provide a prioritised list of research themes and topics relative to those themes on disability and development for DFID's consideration.
2.   To provide a broader view of perceived needs for disability research from different groups of stakeholders.
3.   To indicate what would be the most appropriate modalities for carrying out the suggested research.

The process

Who, where and how
The work was done jointly by disabled researchers in the North and in the South. The latter worked with a wide variety of stakeholders, including DPOs, in South Africa, Uganda, Zambia, Malawi, Lesotho Zimbabwe, Bangladesh and Afghanistan.

Difficulties with the process
Many topics identified were already flagged up at the Malawi Roundtable, which helped set the agenda for the entire KaR research programme. Furthermore, most people questioned were relatively unaware of what research had been or was being done. There were also problems with deciding what weight to give to the research suggestions. Nonetheless, despite the difficulties we feel that by engaging with a wide range of stakeholders, especially a broad geographical spread of Southern DPOs, we are able to offer a extremely well-grounded and valuable idea of what research is being called for on disability and development by those to whom it has the most direct relevance.

Research Modalities
We offer a critique of traditional top—down research approach and argue for an emancipatory model in which disabled people take the lead. This idea received strong support from DPOs and their allies. It is also consistent both with DFID's human rights approach to development and the Central Research Department's preference for demand-led research.

Research Themes
We have chosen the topics on the basis of the perceived research needs expressed, particularly by Southern DPOs, DFID's areas of interests and expertise and the suitability of the topics for deploying an emancipatory research agenda.

1.   Researching emancipatory research
A review of the way in which current research funding on disability and development operates could unpick the ways in which disabled people, both in the North and the South, participate in research projects.

2.   Poverty and disability
This was the first major research topic identified by the Malawi Roundtable. DPOs were concerned with researching how to get disability effectively addressed in poverty reduction programmes. Although there was some overlap, agency interest tended to be focused more on being able to have data to make a convincing case for the inclusion of disability in development.

3.   Disability and new aid instruments
Participants at the Malawi Roundtable were conscious that the new aid instruments, particularly as they are focused on pro-poor growth, were one of the main gateways to getting disability on the poverty-reduction agenda.

4.   HIV/AIDs
Research on disability and HIV/AIDs figured prominently in the list of topics from organisations in sub-Saharan Africa. Combating the spread of HIV/AIDs is the sixth MDG and as such is the basis for DFID's overall policy remit. It is also one of DFID's priorities in Southern Africa. Supporting DPOS in research around disability and HIV/AIDs would add a valuable dimension to this work.

5.   Education
With UNICEF estimating that only 3% of disabled children in developing countries attend school and most of these are segregated, it is obvious why education should receive so much attention. Achieving universal primary education is also a principle MDG. To meet this goal for disabled children is going to be a monumental task.

6.   Disasters and post-conflict situations
The KaR project on this subject (Kett, Stubbs and Yeo 2005) has concluded that "There is a vast amount of literature spanning the disciplines of development studies, emergencies and disasters, conflict/refugee situations, disability studies. There is hardly any literature that combines these disciplines and results in useful material on disability in emergency situations in a development context. Inclusive handbooks and manuals do exist but there was little evidence of their use."

7.   Development aid and DPOs/how to strengthen DPOs
The institutionalised asymmetry of resources and power that has been deeply imbedded in the system because of the traditional charity approach to disability

works to keep many DPOs dependent, weak and ineffective both in their ability to be representative and to advocate for the rights of disabled people. The legislation and policy research carried out under the KaR programme has confirmed, that with certain exceptions, this is the true at both national and international levels. Research is, therefore, needed into a whole series of questions which touch on the makeup, role and effectiveness of DPOs.

8. Legislation and policy

If development agencies are going to make any impact with respect to mainstreaming disability in their interventions then their must to some degree be a receptive ideological and legislative environment to feed into. For DFID this is particularly important as more aid is being channelled in ways which make it increasingly difficult to impose conditionality.

Other research topics

There were a great many other research topics suggested by our respondents. The most important one not recommended is around the incidence and prevalence of disability. Although the subject has represented a major lacuna for decades and is often the first one to be sited by respondents, a good deal of research is already under way at an international level and, with few exceptions it has tended to be heavily dominated by national statistical offices.

Conclusion

We have argued that the critical first step to devising a research programme on disability and development is to be absolutely clear on the process or research modalities which will be employed. For the reasons outlined previously, we feel that the most productive way forward is to adopt an emancipatory approach that puts disabled people in the forefront but also embraces genuine partnership working with academics or other professionals.

The Research

Aim of the project

The original aim of the project, in line with the TOR in the research prospectus, was to provide DFID with a comprehensive review of research priorities with respect to mainstreaming disability in development cooperation based on perceived needs and research that has been and is being done. About two months into the work we were asked to broaden our brief and assess the gaps in research with respect to disability and development more generally, review current work being carried out in relation to these gaps, recommend the most fruitful areas for DFID's future research agenda on disability and develop ideas on how the research process should be structured. As explained below, this meant a substantive change in our research plans, research processes and deliverable outcomes.

Expected outcomes

As set out in our proposal, the main outcomes which we agreed to deliver were:

1.   A selected annotated bibliography of the most significant published work on disability and development where this is directly or indirectly linked to mainstreaming.
2.   A detailed review of current ongoing research on disability and development and mainstreaming taking place in the North and the South.
3.   A informed view from the South of what DPOs see as the gaps in knowledge and research with respect to disability-inclusive development policy and practice and how these can to be filled.
4.   An meta analysis of the findings of other KaR commissioned research and the roundtable meetings.

Under the new remit, we have been obliged to redefine and simplify these outcomes. These are now:

1. To provide a prioritised list of research themes and topics relative to those themes on disability and development for DFID's consideration.
2. To provide a broader view of perceived needs for disability research from different groups of stakeholders.
3. To indicate what would be the most appropriate modalities for carrying out the suggested research.

In light of this far broader remit it was not possible to carry out a detailed bibliographical review for each major research theme identified.

The process

Who, where and how

The work was done jointly by disabled researchers in the North and in the South. The latter worked with a wide variety of stakeholders, including DPOs, in South Africa, Uganda, Zambia, Malawi, Lesotho Zimbabwe, Bangladesh and Afghanistan. In the North we held in-depth interviews at USAID, DFID and the World Bank (see Appendix 6), as well as discussions with DPOs, NGOs and many individuals working in the field of disability and development. (see Appendix 1) A variety of methods were employed, including; semi-structured interviews, questionnaires, telephone conversations, email, and meetings.

We had intended to set up reference groups among Southern DPOs, whose role, besides guiding the research, would have been to ensure that the key principles set out at the Malawi Roundtable[1] (see below), particularly the empowerment of and benefit to disabled people, were sustained. Unfortunately,

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[1] The Malawi Roundtable ("Disability, poverty and the Millennium Development Goals") was held in Lilongwe 2nd to 4th November 2004. It was part of the Disability KaR programme. There were 39 participants, 18 from Malawi. They included the government's disability advisory together with representatives from ministries, NGOs and regional, national and grassroots' disabled people's organisations (DPOs). Of the latter representatives attended from India, Cambodia, Zimbabwe, Zambia, Swaziland, Uganda, Tanzania, South Africa and Namibia.

because this project had to be carried out so hurriedly and the TORs were altered, instead of the desired sequential process of having the work informed from the onset by the DPO reference groups, all parts of the project in the North and the South have had to be undertaken simultaneously.

Guiding Principles for Research Agreed at

the Malawi Roundtable

RESEARCH SHOULD …

- *benefit disabled people*

- *be empowering*

- *include knowledgeable and skilled disabled people relevant to the topic*

- *be inclusive of all disabilities within the range of research topics*

- *be rigorous and unbiased, methodical and analytical*

- *be specific and focused*

- *be action oriented*

- *have a clear plan for dissemination and utilisation*

- *be gender sensitive*

We spent a considerable time putting together a detailed, carefully structured approach and questionnaire around mainstreaming disability in development cooperation that sought to discover how the concept was understood, what was already known, what research would help practically to take forward a mainstreaming agenda, and how that research should be conducted. Our approach was based on a gender-mainstreaming model and would have allowed us to work through in a clear and methodical manner research appropriate to the different but interrelated aspects of the mainstreaming process. Once that objective was abandoned, and given the limited time and resources at our disposal, we were obliged to move to a more simple set of questions (see below). However, because at that point, about a third of the way into the project, a considerable amount of the data collection was already ongoing it was unavoidable that our results contain elements of both a focus on mainstreaming and the final broader-based research remit.

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Quick Questions on Research Gaps

DFID wants to discover what are the most important research themes on disability and development which need to be supported. They are also interested in the most effective research process which will deliver demand-led research within a framework which is emancipatory.

1.   What is your wish list of the most important research themes around disability and development that you would like to see undertaken and you feel would be of most value for disabled people?

2.   What do you see as the role of DPOs in this research process?

3.   How can that role be supported by development agencies?

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Difficulties with the process

Having to ask essentially for an open wish list of research themes and topics turned out to be somewhat problematic. For example, each respondent tended, not unreasonably, to identify issues of immediate importance for them, their organisation and/or disabled people in their country. Common subjects did emerge, but there were also a great number of more narrowly defined, either country or impairment-specific, projects. While these could be viewed as parochial and not worthy of consideration on a global research playing field, they are important to disabled people who face the issues on a daily basis. For this reason alone they deserve to be highlighted and set out for consideration. We do this at the end of this report.

Secondly, our initial questionnaire was constructed to enable even those without direct experience of disability to identify, through their experience with development work, how disability might be incorporated in that work. The wish-list approach, on the other hand, frequently led to very generalised research being indicated and, consequently, in many instances added little of value to our investigations. Furthermore, the main themes given here offer no surprises, the majority having been called for at the Malawi Roundtable and many of these already well trailed by others. As will be explained, our most significant findings are about the nature of the research process itself.

Another difficulty was that most people questioned were relatively unaware of what research had been or was being done. This was particularly the case for those who did not have a specialist knowledge of the field, including many working in development agencies. It was also true for many DPOs. (see Appendix 10) In most instances the latter had a clear idea of their particular

research requirements but were not well placed or did not have the resources to access research findings or knowledge about ongoing projects. Even at the World Bank, where awareness of current research is the most comprehensive, it was conceded that keeping track of who was doing what with respect to research was a "major headache". Not surprisingly, we had the same problem in trying to match what research people felt was needed with what had been done and not yet published or was at this time being carried out. However, in Bangladesh and Afghanistan we were fortunate to be able to catalogue a number of disability and development research projects. (see Appendix 8 and 9)

As suggested above, we faced the question of what weight to give to the suggestions we received. Clearly we could not judge significance by simply counting how many times people asked for a particular piece of research. How does one judge the relative importance of the opinion a development economist or a statistician, often with little direct experience of disability in the South, with a DPO in Bangladesh or Zambia which does have that experience but is unlikely to have or have access to the same level of economic or statistical skills? This is a question we consider when looking at the research process.

As mentioned above, most of the research gaps identified by the wide range of stakeholders had already been flagged up, often in some detail, by participants at the Malawi Roundtable (see Appendix 2). We see our task here as setting these out once more, indicating what other groups demanded similar topics and why, and indicating what relevant research has already been or is being done.

Finally, despite the difficulties set out here, we feel that by engaging with a wide range of stakeholders, especially a broad geographical spread of Southern DPOs, we are able to offer a extremely well-grounded and valuable idea of what research is being called for on disability and development by those to whom it has the most direct relevance. However, before considering this, we first want to explore the research process itself.

Research Modalities

For many of the reasons outline above, we have concluded that the most significant contribution of our investigation centres on the research process rather than on particular themes or topics. Of course, this is not to say these are unimportant. They are and will be discussed. We begin, however, with a consideration of the way in which most research is developed and carried out and suggest an alternative method that conforms to both DFID's human rights approach to development and the Central Research Department's emphasis on research being participatory, relevant and demand led. We then want to use this as a key criteria for priortising research themes and topics.

In November 2004, the Disability and Development Team at the World Bank 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) A summary of the meeting's conclusions is given below. (World Bank 2005) Reviewing notes of the meeting, there is no doubt that the discussions were informative and have given the Bank a sound platform for

moving ahead. However, one key element seems to have been missing from these deliberations, 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 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.

Summary of findings
World Bank's Disability and Development
Research Agenda Meeting Nov. 14th 2004

The general consensus for disability research boils down to three things:

1)   We should conduct a detailed program evaluation of some service delivery in the area of employment, education, or health.
2)   This evaluation should focus on the family (or household) of the disabled person.
3)   It would be best if this study were incorporated with current operations in some manner and if it drew upon current efforts in standardize disability measurement

Overall, there are three basic areas of research:

1)   Evaluating efforts to promote equal outcomes for people with disabilities
2)   Evaluating efforts to prevent disabilities
3)   Evaluating efforts to provide social protection services that include disabled people and/or target them directly.

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), although these are generally associated, especially the latter's PLA (Participatory Learning Approaches) and PRA (Participatory Rural Appraisal), with research in the field. 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 in 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 undated) If, at the very least, disabled people are not 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.

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, to emancipate and not 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 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 with and in the response to questionnaires from all the southern DPOs. 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."

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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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Zimbabwe DPOs role in the research process

Response	N	%
To be on the forefront	8	90
DPs to be researchers	10	100
DPOs should take a leading role	9	90
DPOs to take an advisory role	9	90
DPs should be team leaders in e research programmes	7	70

In Bangladesh a workshop was organised by the National Grass-root Disabled Federation of Bangladesh together with Action on Disability and Development to discuss research priorities (see Appendix 3). 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

on disability issue. (Appendix 4) 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 lead roll 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, backing this kind of top-down, paternalistic approach. In what appears to be 'business-as-usual' they are funding Handicap International and Christoffel-Blindenmission, another large INGO, to "…develop a framework for inclusion of disability in PRSPs."[2] 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. While this is strictly speaking a project more than research per se, the same issues of control apply. 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 the 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 take 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 president of the World Bank has said on numerous occasions, without including them in the development agenda the MDGs will not be

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[2] E-mail correspondence (June 9th 2005) on the Global Partnership for Disability and Development list. We say 'appears' because we do not have any more information than that contained in the message. Also, we are not decrying the involvement of such INGOs, only the dominant position of power and control they traditionally assume.

achieved.

Research Themes

We do not intend to offer a detailed analysis of the every research topic suggested or even the principle research themes, as each could provide the basis for a substantial essay in itself. Instead we will outline eight major themes, drawing heavily, although not exclusively, on the list developed at the Malawi Roundtable, which we feel would be most suitable for DFID to support. We will also indicate, as far as we could discover, any work currently underway or recently completed relating to them. We have chosen the topics on the basis of the perceived research needs expressed, particularly by Southern DPOs (for details see appendices), DFID's areas of interests and expertise and the suitability of the topics for deploying an emancipatory research agenda.

1.   Researching emancipatory research

Much has been written about emancipatory research (Barnes 2003), but we were unable to find any research done specifically around this topic in relation to Southern DPOs. In interviews, workshops and answers to questionnaires, as indicated above, there was a strong demand for this kind of approach. There was also a good deal of comment by DPOs on the need for basic funding and capacity building of their organisations so they could assume a more central role in the research process. While often referring more to project than specifically research funding, there was also demands for direct funding for DPOs rather than having this done through the mediation of INGOs. It was claimed that as long as DPOs were simply used as participants they could never build their own skills and organisational capacity.

A review of the way in which current research funding on disability and development operates could unpick the ways in which disabled people, both in the North and the South, participate in research projects. Among the issues to consider would be the respective roles played by funders, INGOs and DPOs in both the application process and research implementation, how grounded it is disabled people's experience, how the research is directed and the outputs disseminated as well as the power of the research to initiate sustainable change and more generally build the capacity of the DPOs. The research could also look more closely at how DPOs could be best be supported to take a more leading role. The Rowntree-funded report mentioned above (Hanley 2005), would serve as a good model for this work not only because of its findings, but also because it was conducted within a emancipatory-research framework.

As we have argued, emancipatory research fits neatly with DFID's commitment to a human rights' approach to development. This particular research would, therefore, not only be relevant for disability, but also for other areas of concern relating to vulnerable/oppressed groups, such as children, older people, women, ethic minorities, etc.

2.   Poverty and disability

This was the first major research topic identified by the Malawi Roundtable. It is interesting that there was no question among Southern DPOs, that poverty was a major problem for disabled people. Rather they were concerned with how to get disabled people more fully recognised as part of this agenda, particularly as poverty reduction is the central MDG, and disability is not mentioned. In practical terms they wanted research about how DPOs could can engage effectively in the PRSP process. This latter request was also made by DPOs in Bangladesh and Uganda. We consider the specific question of aid instruments separately below.

Poverty and disability was also a central research concern for many agencies, particularly the World Bank. But here the emphasis was trying to quantify the relationship between the two in order to convince their organisations or governments that disability was worthy of more serious consideration. For example, besides wanting general quantitative material on disability, the Disability and Development Team are interested in developing standardised modules for the Bank's Living Standards Measurement Surveys (LSMS), household surveys which are one of the Bank's basic means of measuring poverty. However, as Rebecca Yeo has observed, "It is questionable whether it is really a lack of data that is hampering policy makers from including disabled people. However, reliable statistics may help to motivate policy makers to take action." (Yeo 2001)

In 1999 Elwan pointed out while much had been said about how disability and poverty were interlinked, there had been few empirical studies.(Elwan 1999) Since then there have been a number of major studies of living conditions of disabled people in Zimbabwe, Malawi and Namibia (Eide et. al 2003a, 2003b, 2004) based on household surveys and similar work is planned for South Africa and Zambia. These have offered excellent statistics relating to certain poverty indicators around employment, education, etc.. These also represent a start in providing disability-disaggregated data, a key evidence base, as it is for gender, for those wanting to make the case for mainstreaming disability into development. (Albert and Miller 2005)

It is significant that the three completed studies cited above were carried out with the active participation of DPOs. In the first study in Namibia this included DPOs from both the North (Norwegian Federation of People with Disabilities [FFO] and the Atlas Alliance) and South (Southern African Federation of the Disabled [SAFOD] and the National Federation of People with Disabilities in Namibia [NFPDN]). Besides offering valuable data, these and the follow up studies also appears to present a good example of a more genuinely inclusive working, if not empowering relationship. The latter is suggested by the introduction to the last report on Malawi, in which Rachel Kachaje, the chairperson of SAFOD, writes, "People with disabilities have played an active role in all aspects of this study. …FEDOMA had maintained responsibility for project management at the local level. People with disabilities have been equal partners in the design process, in data collection and supervision…". There was also a consciousness of the need to use the findings to stimulate change. At the end of the Malawi study the authors state that, "… it is hoped that this study and

other similar studies can contribute to highlight systematic discrimination, inform the public, authorities and the disabled themselves about the situation, and thus create a consciousness that is necessary for action." (Eide and Loeb 2004 158). In fact, this project itself could would be a suitable case study for the first research theme, not only for the process, but also to investigate what happened after the researchers moved on.

Poverty is the overarching MDG. DFID's PSA is based on the MDGs. Data from the three Southern African reports confirms what was already well known, especially by disabled people – poverty and disability are closely intertwined. If such studies are needed to document this and make the case more emphatic and through this to give DPOs the analytical ammunition to lobby for change then this would be a valuable research theme for DFID to support.

> Depending on how the research is carried out, it can also help to change the power relations that exclude disabled people. Disabled and non-disabled researchers need to work together. An investment of time and financial resources is required before many disabled people will be able to effectively conduct research themselves. A lifetime of exclusion cannot be overcome immediately by one researcher. (Yeo 2001)

3.   Disability and new aid instruments

Participants at the Malawi Roundtable were conscious that the new aid instruments, particularly as they are focused on pro-poor growth, were one of the main gateways to getting disability on the poverty-reduction agenda. They therefore asked for more research on ways this could be accomplished. This was an issue which was also mentioned by many of our respondents across all the groups surveyed. This concern is hardly surprising as since 1999, when they were first introduced, an increasing proportion of aid has been channelled through these new instruments and associated processes, particularly for the poorest countries.

To date disability has been extremely ill served by the vast majority of PRSPs. If it finds a mention it is generally with respect to social protection or disabled people are lumped in with other vulnerable groups. An ILO study (ILO 2002) found that disability had been almost totally excluded from the first round of PRSPs. There has been some improvement in the following rounds, but an authoritative report published in 2004 still characterised the coverage of disability as limited and a "… patchwork of fragmented and uncoordinated interventions…". (World Bank 2004a)

It is not only the PRSPs that are at issue. There are the upstream processes, such as Country Assessments and Country Development Framework as well as key guidance documents like the PRSP Sourcebook. At the moment none of these have any reference to disability. There are also downstream instruments such as Country Assistance Strategies (CAS) and Poverty Reduction Support Credits (PRSCs) through which the PRSPs are implemented. Here too, even when disability might be mentioned in the PRSP, there are few examples of this being carried through to the next stage.

The World Bank has funded training for DPOs on PRSPs, but this has just begun and remains to be evaluated. Interviews with SDA's at DFID have indicated that there are concerns about how other cross-cutting issues such as gender are being marginalised within the new aid instruments. DPOs, as part of civil society, need to be empowered to take a more meaningful role in the PRSP process. The World Bank report is particularly strong on this, saying:

> *An important lesson that emerged from the review of PRSPs is that the involvement of disabled persons in the preparation of PRSPs provided substantial benefits. The main result was to increase the focus of the PRSPs' interventions on the area that matter the most to disabled persons, namely the lack of access to employment. In contrast, whenever disabled persons were not strongly involved, the economic focus of disability interventions remained weak…"* (World Bank 2004a vii)

Just as it is important for disabled people to be more involved in PRSPs, they also need to take a lead role in research or project work around the most effective ways to enable this involvement. A report carried out by A.K. Dube on Participation of Disabled People in the PRSP/PEAP Process in Uganda as part of the KaR programme (Dube 2005) offers an excellent example of this process. The World Bank-funded project in Tanzania, referred to above, seems cast in a more traditional mode. As DFID's chief remit is poverty reduction and it is concentrating increasingly on HIPCs where PRSPs are relevant, this area of disability research would offer particularly added value.

4.   HIV/AIDs

Research on disability and HIV/AIDs figured prominently in the list of topics from organisations in sub-Saharan Africa. At the Malawi Roundtable they asked for specific research on a number of topics. (see box) In Zimbabwe all DPOs wanted to see work on this, as well as the related subject of sexual violence against disabled women. Interestingly, this did not figure on the wish list in Zambia or, less surprisingly, of those in Afghanistan or Bangladesh.

Research on HIV/AIDS – Malawi Roundtable
- Survey of the literature related to HIV/AIDS and disability
- How far are HIV/AIDS programmes aware of disability and how far are disability programmes and DPOs aware of HIV/AIDS issues?
- What is the impact of HIV/AIDS on people with disabilities?
- How can DPOs become engaged in the campaign against HIV/AIDS?

It is widely recognised that HIV/AIDs is a critical problem for disabled people in sub-Saharan Africa. (Sweeny 2004). In 2003 Groce wrote that, "There is a real need to understand the issue of HIV/AIDS for disabled people in global terms

and to design and implement programmes and policy in a more coherent and comprehensive manner. The roughly 600 million individuals who live with a disability are among the poorest, least educated, and most marginalised of all the world's peoples. They are at serious risk of HIV/AIDS and attention needs to be focused on them." (Groce 2003)

It appears that a considerable amount of research has and is being done in this area. For example, the Disability and Development Team at the World Bank as well as the Bank's Global HIV/AIDs Program support the HIV/AIDS Global Survey located at the Yale University School of Public Health. Their remit is to "… identify, foster and disseminate research, policies and programmatic interventions concerning the impact of HIV/AIDS on populations with physical, sensory (deaf, blind), intellectual and mental health disabilities. This program is concerned both with improving HIV/AIDs prevention efforts for children, adolescents and adults with disability and in improving services and support for those individuals with disability who are HIV positive ." (http://globalsurvey.med.yale.edu/) They recently published, HIV/AIDS and Disability. Capturing Hidden Voices (Groce 2004), which sets out the global scope of the problem and calls for more action and more information.

DPOs in Africa have been active in research on this subject. For example, NUDIPU has undertaken a number of projects on disability and HIV/AIDs (See box). SAFOD, DPSA and NFPDN (see websites) have all promoted work on HIV/AIDS.

Combating the spread of HIV/AIDs is the sixth MDG and as such is the basis for DFID's overall policy remit. It is also one of DFID's priorities in Southern Africa. Supporting DPOS in research around disability and HIV/AIDs would add a valuable dimension to this work. However, given the amount of research that has already been done on this, a necessary first step would be to commission a comprehensive literature review as suggested by the Malawi Roundtable.

Research by NUDIPU on disability and HIV/AIDs

(a) A situational analysis on the Community of People with disabilities in the three districts.
(b) A study to assess to knowledge about HIV/AIDS, Access to HIV/AIDS Service and Vulnerability of Young People with Disabilities
(c) A desk study on the level of knowledge and access to HIV/AIDS information and services by people with disabilities in Uganda.
(NUDIPU – 2004)

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5.   Education

The one disability and development topic which seems to have generated more research than HIV/AIDs is education. Despite, or possibly because of this, it figures on almost everyone's list of research priorities. With UNICEF estimating that only 3% of disabled children in developing countries attend school and most of these are segregated, it is obvious why education should receive so much

attention. Achieving universal primary education is also a principle MDG. To meet this goal for disabled children is going to be a monumental task.

While many of our respondents put this down as a general theme, for others the topics were quite specific. For example, ZAFOD listed twelve different areas that they felt should be examined, from how many children attended mainstream schools to whether schools were accessible. (See Appendix 5). Education was also highlighted as a priority by DPOs in Bangladesh and Afghanistan.

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Research on education – Malawi Roundtable

- What are the shortfalls that exist in the design and implementation of education for disabled children?
- What has the impact of inclusive education been – needs to be measured in terms of enrolment, repetition and drop out rates.
- What is the impact of special versus inclusive/integrated education that children with disabilities receive?
- How relevant is the education that children with disabilities receive?

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There are generic issues around inclusive education, but much of the detailed research called for is country-specific. In a companion study on education for the KaR programme (which was a direct response to the Malawi Roundtable research request), the authors recommend that, among other things, country wide baseline situation analyses on disability issue are needed for each country they surveyed – South Africa, Nepal, Bangladesh and Vietnam.

We feel that research on education and disability works well with DFID's policy links with the MDGs and the fact that it has estimated it will spend one billion pounds on education between 2004 and 2008. Not only do specific issues around inclusive education need to be investigated but disability should be mainstreamed into educational research generally, thus replicating the twin-track approach that had been suggested in DFID's issue paper on disability and development. (DFID 2000) Finally, as with research on HIV/AIDs, because of both the volume of research and the national specificity of education systems, before any research could be commissioned a detailed research review needs to be done.

6.   Disasters and post-conflict situations

In conflicts and disasters it is well known that poor people, living in the most vulnerable areas and already living on the narrowest of margins are always badly effected. It does not take a great deal of imagination to understand why disabled people, who generally are the poorest of the poor and already socially excluded usually find themselves worst off than anyone when political or environmental conditions suddenly deteriorate. This is one reason why the Malawi Roundtable identified this theme as important and it became one of the research projects

funded by the KaR. Other respondents also indicated that this was a high-priority area to research including the World Bank and the Atlas Alliance (Norway) and DPOs in Afghanistan and Uganda, where the reason for latter's concern is obvious. In the former country, DPO leaders asked for "Research on mainstreaming – what to be done and how it meet the needs of disabled people in the post conflict Afghan society where war continued for 25 years."

**Research on humanitarian and post conflict
– Malawi Roundtable**

- What is the effectiveness and relevance of mine action programmes on the disability sector?
- To what extent do post conflict strategies/ the war on terror / disaster preparedness planning / humanitarian aid include and deal with the needs of people with disabilities?

The KaR project on this subject (Kett, Stubbs and Yeo 2005) has concluded that "There is a vast amount of literature spanning the disciplines of development studies, emergencies and disasters, conflict/refugee situations, disability studies. There is hardly any literature that combines these disciplines and results in useful material on disability in emergency situations in a development context. Inclusive handbooks and manuals do exist but there was little evidence of their use." From their work a number of specific areas that warrant further research have been identified. These include research on; how to refine and publicise social model data collection systems, what are the institutional and organisational barriers to inclusion, who does needs assessments, with who and how is consultation being done, what are the links between marginalised groups, how can research being linked to action and what is the relationship between INGOs and local DPOs. It is also important to investigate how disability can be mainstreamed into the work disaster relief and post-conflict work of development agencies.

DFID assumes a leading international role in humanitarian relief efforts. Further, they recognize that "A major obstacle (to achieving the MDGs) is persistent or recurrent humanitarian emergencies, resulting from violent conflict as well as natural disasters."[3] The research outlined above would help to take this agenda forward by making it more inclusive. It is also a field that cries out for emancipatory research, as so much of the current practice is to "do to" rather than "do with" people caught up in these situations.

7.   Development aid and DPOs/how to strengthen DPOs

We have argued that in line with an emancipatory model it is essential to ground research on disability and development, as well as project work, in the lived experience of disabled people. This is the only way the processes will be relevant, the outputs owned by those involved as well as having the possibility of

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[3] http://www.dfid.gov.uk/aboutdfid/organisation/conflicthumanitarianassistance.asp

these outputs being sustained as outcomes. It is also the best method of meeting the key criteria laid down for DFID's human rights approach.

**Research on development aid and DPOs –
Malawi Roundtable**

- What has been/is the purpose and effectiveness of aid to DPOs?
- What is the capacity of development agencies to deliver aid to DPOs effectively (ie how proposals from DPOs are assessed).
- Exploration of donor funding trends in relation to disability and how changes in the trends affect the delivery of aid.

However, for this to happen DPOs, both North and South, need to have the capacity to carry out the work. At the moment, despite the UN's call for their state support, (see below) almost all DPOs continually have to struggle to find basic funding and they are often expected to input into development cooperation or national government consultations on a voluntary basis. This puts them at a substantial disadvantage in relation to the better-funded INGO sector, as the latter have the capacity to put paid-professionals at the table as well as to bid more effectively for grants and contracts. This institutionalised asymmetry of resources and power that has been deeply imbedded in the system because of the traditional charity approach to disability works to keep many DPOs dependent, weak and ineffective both in their ability to be representative and to advocate for the rights of disabled people. The legislation and policy research carried out under the KaR programme has confirmed, that with certain exceptions, this is the true at both national and international levels.

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities
Extract from Standard Rule 18
- States should recognize the right of the organizations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognize the advisory role of organizations of persons with disabilities in decision-making on disability matters.
- States should encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and/or advocates. States should recognize that those organizations have a role to play in the development of disability policy.

Research is, therefore, needed into a whole series of questions which touch on the makeup, role and effectiveness of DPOs. What do DPOs want with respect to their own development? How are they funded? What difficulties do they experience in being active in development work? What is their relationship with development agencies, INGOs and domestic NGOs? In what ways do they interact with national governments? Do they genuinely represent and are they

accountable to disabled people? What would be the most effective way to assist DPOs to improve their performance? How can DPOs in the North and South work more effectively together?

There are some excellent examples which could provide the starting point for this research, including the way disabled people are included root and branch in the political structure in Uganda or the close links between the movement and the state in South Africa.

In the North, a model to explore could be the way in which many Nordic DPOs are core funded by government and what this means in terms addressing disability and development issues. Also most of these Northern DPOs have close working relationships with their Southern counterparts and this also deserves to be explored more systematically. For example, in a recent report commissioned by the KaR, it was found that DPOs in Mozambique found working with Northern DPOs much more satisfactory than with Northern NGOs. The former they felt had a shared understanding of the issues facing disabled people, while the latter tended to treat them as "… clients and objects of capacity building, not equal partners." (Ncube 2005) It would be instructive to see if this perception was more widely shared in other countries and regions and if so what it might mean in terms of reassessing how aid is delivered to disabled people in the South.

If DFID was to push ahead with an emancipatory research agenda for disability and development this area would be of critical importance to explore as a necessary compliment to work on the research process itself as outlined in the first theme mentioned above.

8   Legislation and policy

If development agencies are going to make any impact with respect to mainstreaming disability in their interventions then their must to some degree be a receptive ideological and legislative environment to feed into. For DFID this is particularly important as more aid is being channelled in ways which make it increasingly difficult to impose conditionality. This is one reason why investigating disability legislation and policies in recipient countries is so important in terms of development cooperation. Another is that given DFID's human rights approach it is critical to see how fundamental human rights are enshrined in domestic legislation and policies how these are or are not being implemented

In response to the Malawi Roundtable's highlighting of this question the KaR funded a research project on legislation and policy which found, among other things, that:

> *"There has been a welcome increase in awareness of disability as a civil rights issue by governments and policy-makers, with a concomitant growth in the enactment of legislation to protect such rights. However, it is clear that legislation is invariably inadequately funded and/or subject to ineffective monitoring and*

enforcement. It appears that the mechanisms that exist in the areas examined as part of this project place too much reliance on disabled people's good will and voluntary effort.." (Hurst, et. al 2005)

**Research on legislation and policy –
Malawi Roundtable**

- What is the role of disability legislation and policies?
- What has the impact of the DPOs been in securing legislation and policies?
- What has the impact of legislation and policy on the disability movement been?

A separate KaR commissioned piece of work on the role and effectiveness of disability legislation in South Africa (Dube 2005b) confirms these results, claiming that while the country has excellent policies, in most cases implementation has been fragmented and inadequate. A recent large-scale survey of 24 Latin American countries concluded similarly for this region that, "The sad fact is that, as this report documents, few countries show signs of thinking about or planning to include people with disabilities in national life. People with disabilities are often invisible. Ignored by policy makers and planners, warehoused in institutions, forgotten, neglected and frequently abused." (IDRM 2004)

There is a need for more country-based in-depth analyses of how and why disability legislation and policies are or are not being implemented. From DFID's perspective it is critical to understand the way in which the legislative environment in each country interacts with development projects and/or other forms of assistance. While this kind of enquiry is particularly well-suited for an emancipatory approach, there are potential dangers. This point emerged from the KaR legislation and policy project and is both concerning and suggests why such work is required. They observe that, "The generally precarious position of disabled peoples' organisations [DPOs] in the policy process has been highlighted by the fear, expressed by a number of respondents, that candid responses to the project survey would result in recriminations." (Hurst et al. 2005)

Other research topics

There were a great many other research topics suggested by our respondents. We have included some of the most significant of these in the table below (too be completed). But, we need to say something more about the one topic which almost everyone mentioned, and which we have not recommended as appropriate for DFID to lead on - **the incidence and prevalence of disability**.

This subject has represented a major lacuna for decades and is often the first one to be sited by respondents. Development agency staff were particularly

interested in this, but many DPOs also said that they needed to have reliable data so as to convince their governments disability was an important question. Some governmental bodies maintained that such statistical information was essential so they could plan appropriate services. They particularly wanted to know many people there were who were blind, deaf, physically impaired, had learning difficulties etc. This raises the contentious question of what is being measured, impairment (sensory, physical, mental conditions) or disability (the negative impact of the environment, attitudes and society on people with impairments). Despite the ICF (see below) this is unresolved and is likely to remain so.

Data collection – Malawi Roundtable

- What are the best methods of gathering data on the prevalence of disability, for example in national censuses, household surveys, specific studies?
- Country level studies on the causes and prevalence of disability (it was felt that this would not be possible as part of the KaR programme's research).

It is well known that basic disability statistics for developing countries are totally inadequate and despite the new International Classification of Functioning, Disability and Health (ICF), there remain major disagreements about precisely what is being measured. Is it just the numbers of disabled people and their impairments or is it the numbers who cannot or do not receive services, as is done through disaggregated data with other excluded groups, such as women, in statistical evidence regarding the provision of education, housing, benefits, employment etc.?

In 2001 the Washington City Group on Disability Statistics was set up by the UN Statistical Division to develop census data which would be robust and internationally comparable. (WCG 2002) There have been four annual meetings since that time and they have only recently (2005) agreed on both a working definition of disability and what questions to include in national censuses. The World Bank has been one of the key funders of this research and the UK Office of National Statistics (ONS) has been closely involved in the work. While a couple of international DPOs have participated in some of the meetings it is apparent that the Group's agenda is driven primarily by national statistical offices. There have also been country-based data collection projects carried out or in the process of being carried out in Uganda, Bolivia, Ecuador, Brazil, Afghanistan, Brazil and Nicaragua, some supported by the Inter-American Development Bank.[4] The two we have reviewed, Ecuador (Augusta Calle & Molina Yépez, 2005) and Nicaragua (ENDIS 2003), use the ICF as a framework and although participation restriction and other key issues are considered, it would seem that most attention had been given over to cataloguing the incidence of different impairments, rather than exploring in any great depth the process of

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[4] http://www.iadb.org/sds/SOC/publication/gen_6191_4093_e.htm

disablement.

Remit of Washington City Group on Disability Statistics

- Promote regular collection and generation of statistical information on disability in populations by statistical offices around the world;
- Assist countries in the collection of disability information on censuses and within statistical systems in light of limited resources and competing demands regarding issues of national importance; and
- Understand the role of statistical systems in providing information about disability to policy- makers who are engaged in promoting full participation and improving the quality of life among people with disabilities. (WCG, 2002)

Good, reliable statistics are of undoubted importance, but despite the fact the there has been some DPO participation, particularly at the country level, overall this seems to be a heavily top down project. Furthermore, as it appears that this research is already well advanced and the UK's ONS is involved, we can see no substantive research role for DFID at this time.

List of main research topics identified by respondents

Disability in humanitarian and post conflict
Disability and new aid instruments
Poverty and disability (measurements of)
Living conditions of disabled people
HIV/AIDs
Disability and human rights
Disabled women and girls
Baseline surveys, various topics
Costs of inclusion of disability in development programmes/cost of exclusion
Incidence and prevalence of disability
Violence against disabled women
Education (various topics)
Disabled children (various issues)
Access issues (physical/communication/transport)
Employment
Microfinance
DPO capacity/sustainability
Mainstreaming disability by donor agencies
Mainstreaming disability in national policy
Mainstreaming people with severe impairments

Attitudes towards disabled people
Access to mainstream healthcare services
Access to services (general)
Legislation/policy
Impairment causes/prevention
Provision of equipment (wheelchairs, hearing aids, etc.)
Disability and diversity
Disabled people in agriculture
Rehabilitation services
Water and sanitation

(See appendices for additional topics and more detailed breakdown of some of the topics noted above.)

Conclusion

Reviewing the entire field of disability and development research is a massive task. We have not begun to scratch the surface. Furthermore, once beyond broad generic issues such as education, health, human rights and so on, any research which will help make a real difference to the lives of disabled people needs to be firmly grounded in the their life experience. One important reason is that despite international efforts to nail down what disability is, the stubborn reality is that it will always be a culturally specific, often self-identified, category. This does not mean that the collection of statistical data is unimportant. If nothing else, from a human rights perspective, it offers ammunition to get disability more fully on political agendas, both national and international.   And it is this human rights perspective which bridges the diverse realities of disability throughout the world and offers a basis for understanding, action and a direct link with DFID's overarching approach to development.

> There is a saying; a hole makes the entire fabric weaker. It lacks richness, texture, and the strength of diversity. People with disabilities have been left out of the fabric of international human rights. The result is a hole that makes all our rights weaker. The framework of universal human rights will be stronger when people with disabilities are no longer left out and left behind. We all benefit when people with disabilities stand up for our ideals. Dr. William Kennedy Smith (IDRM 2004)

We have argued that the critical first step to devising a research programme on disability and development is to be absolutely clear on the process or research modalities which will be employed. For the reasons outlined previously, we feel that the most productive way forward is to adopt an emancipatory approach that puts disabled people in the forefront but also embraces genuine partnership working with academics or other professionals.

The KaR project has created an important network of disabled researchers in the North and the South, as well as strong working links with DPOs. The wider

research project, of which this gap analysis is part, has also modelled a new way of working which we feel puts DFID is in an excellent position to develop a unique research programme rooted in two of the organisations key values, a human rights approach to development and demand-led research. By ensuring that disabled people are moved upstream in the process this would be consistent with both the demands from Northern and Southern DPOs and bring into play DFID's own commitment of ".. enabling people to realise their rights to participate in, and access information relating to, the decision-making processes which affect their lives."

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Appendix 1

Organisations surveyed

Afghanistan

DPOs
- Afghan National Association of the Blind, ANAB
- National Association of Disabled Women in Afghanistan, NADWA Afghan National Association of the Deaf, ANAD
- Community Development for the Disabled, CCD
- Afghan Disability Union, ADU

Government Departments
- Ministry of Labour and Social Welfare
- Ministry of Martyrs and Disabled
- Ministry of Education

Independent Organization and NGOs:
- Afghan Independent Human Rights Commission (AIHRC)
- Afghan Research and Evaluation Unit (AREU)
- Handicap International –France, Afghanistan

International Organizations and UN:
- European Commission Delegation to Afghanistan
- National Programme for Action on Disability (NPAD)/UNDP
- Royal Norwegian Embassy,
- UNICEF Afghanistan
- USAID Afghanistan

Bangladesh

DPOs
- National Grassroots Disability Federation (NGDF): 24 representatives of DPOs/ Union Federations took part in the workshop. (See Appendix for details)

Government Department
- Department of Social Service, Ministry of Social Welfare

Donor Agency
- USAID Bangladesh

NGOs
- The Hunger Project

Research Organizations
- Bangladesh Unnayan Parishad (BUP)

- Research Initiatives in Bangladesh (RIB)
- Bangladesh Institute of Development Studies (BIDS)

Disability Organizations
- Action on Disability and Development (ADD)
- National Forum of Organizations Working with the Disabled (NFOWD
- Centre for the Rehabilitation of the Paralysed (CRP)
- Inter Life Bangladesh (ILB)
- Centre for Services and Information on Disability (CSID)
- Social Assistance for the Rehabilitation of Physically Vulnerable (SARPV)
- Shaw Unnayan

University:
- Dhaka University: Institute of Social Welfare and Research (ISWR)and Institute of Education and Research (IER)
- Islamic University: Department of Economics

Malawi

- Federation of Disabled Organisations in Malawi (FEDOMA)

Uganda

- National Union of Disabled Persons of Uganda (NUDIPU)
- National Union of Women with Disabilities of Uganda (NUWODU)
- Disabled Women's Network on Reproductive Health
- The Uganda National Association for the Deafblind (UNADB)
- Uganda National Action on Physical Disability
- Blind but Able (BBA)
- Epilepsy Support Association

Zambia

- Zambia National Association Of the Deaf (ZNAD)
- Zambia National Federation Of the Blind
- Zambia National Association of the Hearing Impaired
- Disacare Wheelchair Centre (Lusaka)
- Zambia National Association of the Partially Sighted
- Disability Initiatives Foundation (DIF)
- Zambia National Association of Disabled Women (ZNADWO)
- Zambia Association For Children and Adults with Learning Disabilities
- Zambia Federation of the Disabled (ZAFOD)

Zimbabwe

- Spinal Injury Association of Zimbabwe

- Parents with Children with Disability
- Disabled Women Support Organisation
- National Council for the Blind
- National Council of Disabled Persons of Zimbabwe
- Pan African Federation for Disabled Persons (PAFOD)
- Southern Africa Federation for Disabled Persons (SAFOD)
- The Albino Association of Zimbabwe
- Quadriplegic and Paraplegic Association of Zimbabwe (QUAPAZ)
- Danhiko Project

National and International Donors, DPOs, NGOs

- Action on Disability and Development
- Atlas Alliance (Norway)
- British Council of Disabled People
- DFID
- Disabled Peoples International (DPI)
- Disability Awareness in Action (DAA)
- Dutch Coalition on Disability and Development (DCDD)
- Global Partnership on Disability and Development (email list)
- International Disability and Development Consortium (IDDC) (email list)
- Platform for Disability and Development Cooperation (PHOS) Belgium
- USAID
- World Bank, Disability and Development Team

Individuals and other groups

Annika Nilsson (Sweden)
Benedicte Ingstad (Norway)
Leaders of DPOs from Kenya, Malawi, Cameroon, Namibia, Bangladesh, Cambodia and Holland and NGOs in Bolivia, Kenya and Uganda attending KaR Mainstreaming Disability in Development Course University of East Anglia, May, 2005.

Appendix 2

**Research priorities and guiding principles of research
Malawi Roundtable November 2004**

1. RESEARCH PRIORITIES AND GUIDING PRINCIPLES
Guiding principles for the research were that it should:
• benefit disabled people
• be empowering
• include knowledgeable and skilled disabled people relevant to the topic
• be inclusive of all disabilities within the range of research topics
• be rigourous and unbiased thorough and analytical
• be specific and focused
• be action oriented
• have a clear plan for dissemination and utilisation (funded from the Disability
   KaR research budget)
• be gender sensitive

Ten priority areas for research and related research questions were identified,
along with a group of research questions:

a. **Poverty and disability**
　　• How can disabled people engage in the PRSP processes

b. **Legislation and policy**
　　• What is the role of disability legislation and policies?
　　• What has the role of the disability movement been in securing
　　legislation and policies? This should look at case studies of the role that
　　the disability movement in securing legislation and policy in Senegal.
　　• What has the impact of legislation and policy on the disability movement
　　been? This issue was raised in relation to South Africa, where legislation
　　has meant that skilled people with disabilities have been able to access
　　mainstream jobs, in particular in the government. This has resulted in a
　　"brain drain" from the disability movement, leading to a decreased
　　capacity of DPOs to fulfil their remit.

c. **Development aid and DPOs**
　　• What is the purpose and effectiveness of aid to DPOs?
　　• What is the capacity of development agencies to deliver aid to DPOs
　　effectIvely? (ie how proposals from DPOs are assessed).
　　• Exploration of donor funding trends in relation to disability and how
　　changes in the trends affect the delivery of aid.

d. **Data collection**
　　• What are the best methods of gathering data on the prevalence of
　　disability, for example in national censuses, household surveys, specific
　　studies?
　　• Country level studies on the causes and prevalence of disability (it was

felt that this would not be possible as part of the Disability KaR programme's research).

e. **Prevention of disability**
- What role can DPOs meaningfully play in disability prevention programmes? At present DPOs are not involved in these programmes, however research is needed to highlight whether they have a role to play and if so, what type of role.
- How can DPOs make disability prevention programmes work for them?

f. **Education**
- What are the shortfalls that exist in the design and implementation of education for children with disabilities
- What has the impact of inclusive education been? This needs to be measured in terms of enrolment, repetition and drop out rates.
- What is the impact of special versus inclusive/integrated education that children with disabilities receive?
- How relevant is the education that children with disabilities receive?

g. **Humanitarian situations and conflict**
- What is the effectiveness and relevance of mine action programmes on the disability sector?
- To what extent do post conflict strategies/ the war on terror / disaster preparedness planning / humanitarian aid include and deal with the needs of people with disabilities?

h. **HIV/AIDS**
- Survey and synthesis of the literature related to HIV/AIDS and disability
- How far are HIV/AIDS programmes aware of disability and how far are disability programmes and DPOs aware of HIV/AIDS issues?
- What is the impact of HIV/AIDS on people with disabilities?
- How can DPOs become engaged in the campaign against HIV/AIDS?

i. **DPOs**
- How and what can the disability movement learn from other liberation movements, for example around organisational development, youth, succession cycles and intra-disability effectiveness?

j. **Transport**
- What are the transport barriers faced by disabled people in their daily lives (survey and report)?

k. **Others**
- Institutional strengthening of organisations in terms of advocacy (needs assessment and report)
- How low cost demonstration projects in health, education and transport are inclusive of the needs of people with disabilities

Appendix 3

**Workshop on
Research Gap Analysis with DPO Representatives
April 19 2004, Rajshahi Bangladesh**

A workshop with DPOs leaders was held to identify the areas where and what kind of research should be conducted for mainstreaming disability. ADD conducted the research with National Grass-root Disabled Federation of Bangladesh where disabled people recognized research needs and types of research to be done for mainstreaming of disability. The findings of workshops on research gap analysis will guide towards further researches on disability issues in future. Total 27 participants including two facilitators Country Representative and Human Rights Officer of ADD Bangladesh have participated in the workshop. The disabled people actively take part in the analysis into small group discussion and plenary.

At beginning of the workshop, participants were briefed on research, methodologies, dissemination of findings and other relevant activities including advocacy. Then they gave their views on mainstreaming, analysed the present situation and suggested for disability inclusive policy and practice. They identified the research priority and their role in the research process.

What DPOs would like to see in terms of a more disability inclusive development policy and practice?

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a. Understanding of Mainstreaming: What does it mean to DPO leaders?

- There would be no discrimination between disabled and non-disabled. All are equal.
- Everyone will participate at all levels of society according his/her choice without facing any barrier.
- Disabled people will live with dignity in the society where there would be no obstacle, and walls for inclusion.
- Disabled people will able to establish/enjoy their rights and give their opinions.
- Disabled people will be included in all development activities of the states as well as take part in the policy formulation process including representation in parliament.
- All Disabled people irrespective of their impairment, geographical coverage from the grassroots to the urban areas will be included in the development programme of the country.

b. Situation of the present development policies and practices are:

The government development programme such as education, health, employment, skilled manpower development, ICT services do not include Disabled people.

The infrastructure of the country such buildings, transportation, communication, sanitation, water system are not accessible for Disabled people;

Disabled people have less participation and tokenism in amendment and implementation of disability policies, laws and in the process of PRSP development and MDG monitoring.

The development agencies and NGOs provide services to the poor people, imposes their ideas on the marginalized people focus on Microcredit for development. There is no participation of the target people including Disabled people in the decision making and implementation. All the decisions come from the upper level.

What would be more disability inclusive development policies and practice?

- **Law/legislations and infrastructure of the government:**
  - Disability Welfare Act-2001 has to be amended and implemented on the basis of Disabled peoples opinion and participation.
  - Introduce obligation to implement the disability law and provision of punishment if the disability law is not followed.
  - People with learning difficulties and hearing loss should have legal rights to witness in the court while the disabled women and children are victim of violence.
  - Accessibility for disabled people should be ensured in all kind of infrastructure, i.e. ramps in the public buildings,
  - At least 5% of the national budget should allocated for disabled people
  - Representative of disabled people in the decision making process including parliament
  - Priorities for disabled people in all government provision and services

- **Education, Health and Employment:**
  - Sign language and Braille should be introduced in mainstream education system.
  - Teachers should be trained and materials should be provided for education of disabled children into the existing schools
  - Disabled people should receive education free of cost and poor disabled people should get stipend to meet other cost for continuing their studies.

- Education of disabled people should go under the Ministry of Education while the present practice is that Ministry of Social Welfare deal with education of disabled people
- Health services should be accessible for all disabled people
- All doctors, nurse should learn disability issues and they should be disability sensitive
- Bed/seat should allotted for disabled people at the central and district hospitals
- Disabled people will be provided jobs according to their qualification and capacity
- Disabled people will be trained and provided capital for self-employment
- Participation of disabled people the committees of education, health and employmnet

- **Transportation, ICT and Media**
  - Accessibility should be ensured the manufacturing and importing of bus, trains
  - Road construction, traffic system will be consistent with disability
  - Reserved seat and reduced fare should be introduced in the public and private transport
  - Transport workers would be orientation on disability to provide better services
  - Participation of disabled people in the transport policy development process
  - Disability will be considered in ICT research, soft wear and hard-wear development
  - Disabled people will be trained on ICT and ensure access to internet and computer.
  - Media will broadcast regular programme on the disability issue and lives of disabled people and the programme will be accessible for visually and hearing impaired people
  - Disabled people will take part in the programmes and cultural competition broadcast in the media.

- **Donor's policies and activities:**
  - The development aid that is given by the donors should reach to the grassroots level where the poor disabled people live in
  - The donors that provide fund to NGOs should equally provide fund to DPOs
  - Develop understanding of donors on disability ensuring their participation in the workshops, meetings etc. build rapport between donors and DPOs
  - The donors will give priority on disability while they sign agreement with the government for development cooperation and monitor whether disabled people are benefited or not.

Research Priorities: The representatives of the National Grassroots Disability Federations suggested the following areas for research for disability inclusive development policies and practice:

- The activities of DPOs at the grassroots level and sustainability of the DPOs

- Causes of not implementing the disability welfare act 2001: no participation of Disabled people, slow process of bureaucracy or lack of political commitment in the law making process and implementation

- The Poverty Reduction Strategy Paper (PRSP): inclusion of disability and governments' commitment to implement PRSP or it will remain unused as other disability policy.

- Survey of the impairment, disability and the well –being of Disabled people

- Participation of learning disability and severe Disabled people at every level of the society

- Accessible Infrastructure: measures to be taken for buildings, transportation system etc. to enhance mobility of Disabled people

- ICT for Disabled people: to identify the barriers and solutions to avail the opportunities of information society

- What are the appropriate education practices to ensure education of all disabled children in the urban, rural and remote context? What are the steps and reforms should be taken to combat exclusion of disabled children from mainstream education?

- The steps and strategy for mainstreaming disability in the development process

- Alleviate poverty of Disabled people: strategies for employment opportunities of all kinds of Disabled people in the society.

- Mainstreaming of Disabled people who live in island, remote and hilly area that are the most underdeveloped areas in the context of Bangladesh

- Inclusion of most marginalized Disabled people e.g. hearing impaired, learning disabilities and multiple Disabled people in the development process

- Causes of violence against disabled women and the implications of social and legal actions to protect disabled women from violence and to promote their voice

- Leadership and representation of Disabled people in different arena of the society

- Beliefs and attitude of different part of the society to Disabled people and how to build a society free from prejudice - raise awareness, involve media, include disability in the text books.

- Access to resources: implications of budget allocation for Disabled people to promote their economic, social and cultural rights.

- Priority in the plan and policy of development and donor agencies in development cooperation

- Impact of early marriage as a cause of disability and the effect of dowry for the marriage of disabled women in the context of Bangladesh where disabled women are mostly unmarried, widow, divorced or separated.

- DPOs gave first and foremost priority to conduct research on the implementation Bangladesh Disability Welfare Act-2001: process of development, areas of amendment and ways to implement.

What role DPOs should plan in the research?

1. In the research process, the DPOs arrange opinion survey from grassroots to the national level
2. Collect information and case studies that can be used in the research to provide qualitative data
3. Build capacity of Disabled people who can be involved in the research process
4. Disseminate the research findings to local administration, media, policy makers etc.
5. DPOs conduct research or commission research to find the facts for policy and programme

What resource and skills DPOs need to make a full part in the research?

1. Orientation workshops, meetings to enhance the knowledge of DPOs on the identifying issues and research process
2. Provide training to build skill of DPOs to conduct research; The Universities and research organizations should organize training for DPOs to build their capacity to conduct research
3. The DPOs need assistance, guidance and guideline from researchers to be involved in the research process and to conduct research.
4. Overall, there should be funding provisions for DPOs conduct or commission research

Why research is so important?
- To identify barriers in mainstreaming process
- To advance current movement/process
- To enhance analytical and thinking skills

What are the advantage involving Disabled people in the research?

The Disabled people:
- Provide realistic information from the society and life experience
- Able to find out their own problems, they know better about themselves than others.
- Identify ways to resolve problems.

Participants of the Workshops
National Grassroots Disability Federations (NGDF)

SL.	Name	Origination	Designation
1.	Akter Hossin	NGDF	President
2.	All-Amin	Dhaka	Member
3.	Rumke	Dhaka Women Federation	Convener
4.	Fuglue Shakh	Aungeker Federaton Rajshahi	President
5.	Ateir Rahaman	Zhanidaha Songrame Federation	President
6.	Nuzrul Islam	Magura District Federation	Convener
7.	Shahidul Islam	Norhatto Somaj Kallan Federation	Convener
8.	Rafequl Islam	Rangpur	Volunteer
9.	Jed ali	Kushtia District Disability Federation	President
10.	Ebrahim Hossin	National Federation	Justice Secretary
11.	Rasma Khattun	National G. Disability Federation	Member
12.	Khohenur	Sober Satha Gorbo Federation	Volunteer
13.	Tapushe Bissas	Foridpur Metali Federation	Member
14.	Maherul	Jaypurhat	Member
15.	Abu Daud	NGDF	F&E Secretary
16.	Uma kulsum	District Woman Foram Bogra	President
17.	Ashadul Huqe	Khulna Disability Organization	Volunteer
18.	Moyaj Uddin	Allor Protick Federation, Kushtia	President
19.	Joly Khattun	National Federation	Vice President
20.	Sumsun-nahar	District Federation	C convenor
21.	Monera Khattun	Chapai Nawabgong	Member
22.	Laki	Dinajpur Nari-Foram	Convenor
23.	Firoza Aktter	Vobona Prothebondhe Federation	Convenor
24.	Sumsul Alam	Badhon District Federation,Rajshahi	Convenor

25.	Firoza Aktter	Vobona Prothebondhe Federation	Convenor

Appendix 4

Workshop on
"Research Priorities for Disability and Development"
May 2005, Kabul, Afghanistan

22 disabled leaders from 12 DPOs took part in the workshop to identify research priorities for mainstreaming disability. Their views about mainstreaming and DPOs role are given below:

1.   Understanding of Mainstreaming/Disability Inclusive Policy and Practice:
DPOs leaders suggested following issues for inclusive disability policy and practice:

Policy and Decision Making:
- Inclusive policy is required for development and positive changes for disabled people.
- Access into government departments and services and human rights of disabled people should be guaranteed by the constitution of the country.
- Disabled people must be included in all affairs concerning disability.
- International community, United Nations and the Afghan government should ensure representation of disabled people in all political, social and rehabilitation affairs.
- Opinions and ideas of disabled should be considered in the implementation of laws.
- The policy for education, employment and health should be devised to include disabled people.
- Ensuring rights of disabled people in pension and shelter schemes of the government.
  Disability law will be passed in the parliament to promote and protect rights of disabled people and for inclusion of disabled people in all programs of the governmental.
- Representation of disabled people in all the decision making process including the parliament.

Programme:
- Access disabled people to all social and economic programme and resources.
- Employment opportunities according to skills and qualification.
- Priority should be given to disabled people in all rehabilitation processes.
- Economic empowerment of disabled people in different approaches.
- Awareness on educational, social and cultural rights via media.
- Ensuring access of disabled people to pension and insurance.

- There should not be any differences and discrimination between congenital disability and that affected by war.

Other:
- United Nations convention, international declaration and Islamic tradition specific policies that will guarantee the rights of disabled people must be adopted and implemented
- Following international laws Afghan disabled should be provided a separate pathway
- The UN convention on the rights of disabled people must be supported and signed by the Afghan government.

2. What Research or Data Necessary for Policy and Programme

1. Employment of disabled people: Unemployment is a big issue among the disabled people in Afghanistan. Identify the vocational training that is suitable for disabled people and have demand in the community. For example, workshops for making wheelchair where disabled people will produce wheel chair and distribute and sell among the disabled people or possibility of poultry farming that has demand in the community.

2. Afghan Government have national programme for economic development and reconstruction of the country. How much is allocated for specifically disabled people in the national development budget? Why there is not any allocation for disabled people?

3. Social integration and inclusion of disabled people – need a comprehensive study on the behaviour of the society to the disabled people, believe and attitude that exclude disabled people.

4. Disabled people are vulnerable socially and economically. Introduce social security or safety net programme for disabled people that protect them from vulnerability: allowances or Microcredit for disabled people for economic empowerment as they do not have access to the capital in the resource poor country like Afghanistan.

5. Education for disabled people: suitable curriculum and method for different type of disability such visually impairment, hearing loss and learning disability and building capacity of schools to teach the children with disability.

6. Research on mainstreaming – what to be done and how it meet the needs of disabled people in the post conflict Afghan society where war continued for 25 years.

7. Identify the areas of responsibilities of the Government for disabled people. Why there is no interest or mechanism of the Government for involving disabled people in the mainstream development of the country.

8. Communication and rehabilitation for deaf people who are the most marginalized at different level of impairment, age and culture.

9. Impact of not having a disability law – disabled people are discriminated and face problems within the Government system and UN services in Afghanistan

10. What are the reasons the policy makers do not give emphasis to the disabled people but to the infrastructure of the country. For example the Government spend huge money for de-mining but no emphasis for the rehabilitation of land mine survivors.

11. Research on establishment of a separate ministry for disabled people like Ministry of Martyrs and Disabled (MMD) – it promotes or creates hindrance for mainstreaming. For example, for education disabled people go to aid agencies that refer them to Ministry of Education (MOE). MOE send disabled people to MMD that is just like a bank counter for giving 600 Rupees per month for disabled people.

12. Negative attitude of the community to disabled people and barriers to the services. Create awareness of the community and the disabled people themselves about their rights and responsibilities. The capacity of DPOs to demand from the state and others.

3. What Role of DPOs should play in Research?

In a research process the DPOs can play diversified role as other organizations:

- DPOs have experience and different ideas and views that are very important in a research process. DPOs cover all disabled people including physical, visually and hearing impaired and learning disabilities. They are the data bank. The DPOs can provide good data from their own life experience to conduct any research on disability issue.

- DPOs can participate at every stage of research and the disabled people can be researchers as well.

- DPOs have specific goal and objectives where the government is barrier to achieve these goals. After research DPOs can influence the policy makers for implementation of the research findings to develop policy and programme. DPO can work as pressure group to influence the government to spend more in research and policy.

- The disabled people can perform any role in research and advocacy according to the ability

4. Resource and skill DPOs need to take full part in the research:

To take a full part in the research, the DPO leaders suggested to have the following resources and skills in the context of Afghanistan:

- More cooperation among the disabled people's organizations themselves and they work together for more disability inclusive development policy and practice
- Ability to conduct survey in all the provinces of Afghanistan
- DPOs need support in capacity building and human resource development from the research perspective.
- Expertise in conducting research on disability and development
- They need support for logistic including transport, data processing facilities etc.
- Over all DPOs need fund for doing research and any other work for mainstreaming disability in development cooperation.

List of DPOs Participant
Workshop on Research Priorities for Disability and Development,
10 May 2005, Kabul, Afghanistan

SL.	Name of DPOs	Name of Participant	Designation
1.	Afghan National Association of the Blind, ANAB	Ehshan Fayaz	Director
2.	National Association of Disabled Women in Afghanistan, NADWA	Ms. Nafisa Sultani	Director
	- do -	Ms. Amina	Member
	- do -	Akbar Sahibi	Deputy Director
3.	Afghan National Association of the Deaf, ANAD	Syed Khan Agha	Interpreter
	- do -	Karimullah Khan	Director
4.	ADRDA	M. Kaber	Deputy Director
	- do -	Haji Aqabul Nikmol	Director
5.	NPU	Haji Sayid Macbul	
	- do -	Abdal Metan	
6.	Community Development for the Disabled, CCD	Ms. Najila	Staff
	- do -	Haji Shah	
7.	PCNRMD	Akomod Sipug	
	- do -	Momenkin	
8.	Afghan Disability Union, ADU	Haji Omara Khan	Director
9.	Afghan Association for the Blind, AAB	Mahjob Baqayee	Member
	- do -	Akbar Farasat	Administrator
10.	AABRAR	M. Naser	Member
11.	Afghan DPO	Ali Yamar Hashmond	

	- do -	S. Yosuf	
12.	Afghan DPO	Mohammad Afzal	
	Other Organizatiobs		
13.	Handicap International Afghanistan	Firoz Ali	Assistant
14.	NPAD/ UNDP	Abdul Gaffar	Pro assistant to Special

Appendix 5

Research Priorities Zambian Association of the Disabled

The following constitute the list of the most important research themes around disability and development:

1. Awareness Raising

- How much information about persons with disabilities is disseminated in the local community to disabled people themselves, to local authorities, to all citizens (family, school children, business owners, others)?
- Who is responsible for dissemination of the information on disability and in what form?;
- When and why is the information on disability disseminated?
- Who needs information about disabled people, and in what form?
- What is the role of Zambia Agency for Persons with Disabilities, organizations of disabled people, social and health authorities, school, educational authorities, technical authorities, local community authorities, local leaders, etc in information dissemination?
- What about church and other non-governmental organizations?
- Does the local media carry stories about persons with disabilities, and if so, what kind of stories?
- Are persons with disabilities speaking for themselves?
- Is information on disability given seperately or within the general information

2. Medical Care

- Are disabled people getting the same level of health care as everyone else does?
- How much does the health care system in the community cover?
- Are all the local health care units accessible?

- Is specialist service available to everyone in the local community?
- Does any doctor or nurse know sign language?
- Are there special services available for people with severe disabilities?
- Is there acute mental health service available for people who need it?
- Do the health care professionals have general knowledge about disabled people, or are disabled people only patients?
- How does the early discovery of disability happen in the local community?
- How is the cooperation with disability organizations
- What is the attitude of staff towards persons with disabilities?
- What are organisations such as Disability Agency, DPOs, health care officers, elected officials, local leaders doing?

3. Rehabilitation

- Is there rehabilitation work concerning persons with disabilities in the area?
- What is the quality of rehabilitation in the local community, as concerns disabled people?
- Are there any community based rehabilitation (CBR) projects? What shortcomings are there?
- Are some groups excluded?
- Are rehabilitation services available nearby, or do people have to travel far to get these services?
- Are people allowed to choose the place where they prefer to be rehabilitated?
- Are there daily activities available for mental health clients?
- Are there sufficient physical therapy services available in the local health center?
- Is there financial support available for therapy users?
- What about adaptation training?
- Are disabled people included in local groups for rehabilitation cooperation?
- What kind of private services the local community offers?
- What about the availability of speech therapy, different aids for disabled people, and support services?
- Are there technical devices available, and at what cost?
- What has been the role of the Disability Agency, DPOs, Local Authorities, Local Business Owners, in providing rehabilitation services.

4. Right To Support Services

- Are there services prescribed by law for disabled people in your community, and if so, how is the law applied?
  - Personal assistants?
  - Housing services?
  - Interpreter services?
  - Mobility services?
  - Housing repairs?

- o Different forms of support; nutrition, clothing, devices, and aids?
- o Adaptation training?
- o Counseling and guidance?
- o Peer counseling?
- o Disability benefits?
- o Anything else?
- How are support services of intellectually impaired people organized?
- Housing services: how many people are institutionalized, how many people live in small units, how are families supported?
- Employment and day centers: what are the prerequisites for intellectually impaired peoples' independence.
- How are support services organized for mental health users?
- How much institutional care and how much outpatient care?
- Day centers, employment, organizational activities?
- What is the role of disabled people themselves in planning and organizing the services?
- What has been the role of the Disability Agency, DPOs, Local Authorities, Local Business Owners, in this regard?.

5. Accessibility to Physical Environment and to Information:

- ♦ Which public buildings are accessible?
- ♦ Do persons with disabilities have access to local community administration building, church, movie theatre, other theatres, art exhibitions, concert halls, library, administrational offices, schools?
- ♦ Are parks and streets accessible?
- ♦ Are floors slippery?
- ♦ Are streets muddy?
- ♦ Are there places where to take a rest?
- ♦ What about commercial services?
- ♦ Are shops accessible or not?
- ♦ What about banks, barbershops, etc.
- ♦ What is the attitude of building authorities?
- ♦ Is accessibility important or is it a nuisance?
- ♦ Are people aware of building standards?
- ♦ What kind of standards are there?
- ♦ How well have local designers adapted the disability point of view?
- ♦ Are local disability organizations ever asked for statements?
- ♦ Has anyone with a disability had training in understanding construction drawings?
- ♦ Are the residential buildings in the local community accessible? Do the buildings that have been built by the local community accessible
- ♦ Access to information: How are disabled people told about things that concern them? Are there services in sign language, is there material in Braille or in cassettes for blind people?
- ♦ What about tape recordings and diskettes?
- ♦ Are there enough sign language interpreters?

6. Education

- How many disabled children are integrated into mainstream schools?
- Are there disabled children without access to education?
- Do they have support services in ordinary schools or are they placed in special classes?
- What is the attitude of teachers, headmasters, and other education authorities towards children with disabilities?
- Are the school buildings accessible?
- How is the education of intellectually impaired children organized?
- How many special schools and special classes does the local community have?
- How is the cooperation between parents, disability organizations and teachers?
- What services do disabled children have at school and what services do they lack?
- Where do deaf children go to school?
- Do disabled children have possibilities for higher education - and not only in the traditional professions of disabled people.
- How many schools are in the community? How many of these are primary schools? How many are secondary schools and how many are tertiary?

7. Employment:

- What is the general employment situation in the local community?
- What is the employment situation of disabled people?
- What do the statistics of employment office tell about disabled people?
- What kind of services does the employment office offer?
- Does the employment office have staff available to serve disabled people?
- Are there business owners who are ready to employ disabled people in the local community?
- If not, why?
- What about local authorities?
- What kind of experiences do they have about employing disabled people?
- Are disabled people considered when designing and building workplaces?
- Does the local community offer sheltered employment? What kind of jobs does the sheltered employment have? Are employers aware of disabled peoples possibilities to work?
- How is vocational rehabilitation organized in the local community?
- What does it include?
- How willing are disabled people to work, what prevents employment?
- What major companies and organisations are in the area.

8. Income Maintenance And Social Security

- What is the social status of disabled people in the local community?
- Does the local community have lots of disabled people living on a small pension?

- Are they taken care of? Are there disabled people living in the local community, who cannot afford even the most fundamental things?
- Are disabled people granted any kind of financial support?
- What is the situation of young disabled people? What about mentally disabled people?

9. Family Life And Personal Integrity

- Are there families where one or both spouses are disabled, living in the local community?
- Are there families, where disabled parents have children?
- Do pregnant disabled mothers receive support during their pregnancy?
- Do disabled teenagers get sex education?
- Do parents, who are likely to have a disabled child, receive support during pregnancy?
- Are there biased attitudes towards disability in local community health care?
- Is the general attitude of local authorities and professionals in the local community patronizing and domineering, or is it encouraging and supporting?
- How many disabled people in the local community are institutionalized, especially mentally disabled, intellectually impaired and severely disabled people?
- In what kind of circumstances do they live in the institutions?
- Do people living in institutions have possibilities to form relationships, can couples live in the same room if they wish?
- Can disabled people living in institutions decide themselves on their daily schedule?
- How are disabled people protected from becoming the subjects of abuse by the staff in institutions?
- How are disabled peoples' families supported, or families who have disabled children?
- How are disabled peoples' freedom of choice or privacy improved in institutional care?

10. Culture

- Do disabled people have possibilities to enjoy cultural events?
- Is non accessibility a problem?
- What about blind people in art museums, is touching the art objects allowed?
- Do museums offer tours in sign language or interpreted tours for deaf people?
- Do concert halls or theatres have induction loops for hard of hearing people?
- Can hard of hearing people read the scripts in advance?
- Are audio descriptions of performances available?
- Are disabled people taken into account in educational establishments?

♦ What about art schools, are disabled peoples needs considered of?
♦ Do disabled people have cultural pursuits of their own in the local community?
♦ Are disabled peoples cultural activities supported in addition to other cultural activities?
♦ Are disabled peoples cultural activities considered as real culture, or just as rehabilitation and therapy?

11. Recreation and Sports

♦ Are sport centers, sport grounds, gyms, miniature golf courts, fishing places, nature tracks, stadiums, public swimming pools, discotheques, etc. accessible?
♦ Do the disability organizations and sports clubs in the local community organize physical exercise for disabled people?
♦ Is physical education available for disabled children?
♦ Do disabled children have possibilities for exercising and playing with non disabled children?
♦ Are disabled people accepted in non disabled peoples' organizations?

12. Religion

♦ Are churches, chapels, and parish meeting halls accessible?
♦ When it comes to attitudes, are congregations and religious communities open to disabled people?
♦ Is literature available in Braille, cassettes, and diskettes, do staff know sign language or is there interpreting available?
♦ Are there disabled employees and laymen?

13. Information And Research:

♦ Has the local community studied the circumstances of disabled people?
♦ Have disabled people participated in this study?
♦ Has the local community disseminated information to disabled people about their rights and possibilities?
♦ What about existing services and shortcomings in services?
♦ Are disabled people informed about future plans of their communities, like new buildings, community plans, budgets?
♦ Do local newspapers write about disability related issues, what about disabled people themselves?

14. Policy Making and Planning

♦ Is the local authority aware of the UN Standard Rules?
♦ Can disabled people become elected officials in the local community, do they keep in touch with organizations and other disabled people?
♦ Are political decision makers aware of disability issues, do Disability Agencies and disability organizations frequently discuss with decision makers?

♦ Are local authorities aware of disabled peoples' needs? Are political meetings/debates accessible to disabled people?

15. Legislation

♦ Is there any legislation or policy at local community regarding persons with disabilities

16. Economic Policy

♦ Are disability issues taken into account in the budget of the local community?
♦ Have you compared the costs of institutional care and the costs of living at home?
♦ What are the human rights that you cannot measure with money?

17 Coordination Of Disability Issues

♦ Is the Agency on Disability present at the local community
♦ Does the Agency have goals for disability policy?
♦ Has the council set goals before?
♦ Is the communication good between local authorities and disability organizations?

18. Disability Organizations

♦ What disability organizations are active in the local community, are there any disability groups that lack representation, are the organizations active?
♦ Are disabled people in the majority of the members of these organizations?
♦ What are the prerequisites for the activities of the organizations?
♦ Do the organizations have offices or paid staff?
♦ Does the local community support the work of disability organizations?
♦ Are disabled people themselves, and parents of disabled children fully involved in the decision-making and activities of disability organizations?
♦ Describe the activities of the organizations, what is your opinion of the activities, what should be done?
♦ What about cooperation between disability organizations?
♦ Are disabled people themselves having an impact on policies and programs that directly affect them?

19. Staff Training

♦ What is the education level of staff serving disabled people, and are they aware of disability equality issues?
♦ Does the local community organize staff training in cooperation with disability organizations?
♦ What about the private sector?
♦ Do disabled people receive training that enables them to act as spokespersons in disability issues?

20. Technical and Economic Co-operation

- Is the situation of people with disabilities being considered during the development of all plans for technical and economic co-operation inside and between countries?

- Are people with disabilities being consulted on the design of development projects and involved in carrying them out?

- Are such projects able to improve technical and economic skills to assist people with disabilities to gain employment and achieve equality?

Appendix 6

Research Topics suggested by Disability and Development Team at the World Bank (Judy Heumann and Daniel Mont)

- Quantifying relationship between disability and poverty
- Disability in post conflict situation
- Disability and new aid instruments
- Design assessment to include at beginning of projects to be able to measure change
- Comparable measures of disability
- Qualitative measures of disability
- Longitudinal study to measure the impact of measures in specific areas, health, education, social services in countries where disability interventions had been scaled up
- Cost benefit analysis of costs on excluding or including disabled people in the development process
- Who disabled people are and what effect their impairment has with respect to participation in society
- Developing disability-inclusive tool kits, so disability is seen as a normal part of development work, not an add-on
- What kind of quick fixes would lead to disability inclusion.
- Research into comparative costs of special and mainstream education.
- Research into comparative costs of CBR and institutional care in accession countries in Europe.
- Research on the importance and impact of disability training for agencies
- Research into the role of parents as advocates for disabled children
- Research into effectiveness of training programmes to get disabled people into work and back to work

Appendix 7

Research underway or recently completed in Afghanistan

Recently completed research

Survey on the problems of barrier free access for PWDs in the City of Kabul, Afghanistan, conducted by Afghan Disabled Union, July 2004
Afghan Perception on Disability: a research project on the perceptions and practices regarding disability in Afghanistan, to inform a communication strategy, conducted by Altai Consulting, October 2004.
Physical Accessibility and Disability in Afghanistan – conducted by Steps Consulting Social, March 2005.
Comprehensive Disabled Afghans' Programme, UNDP – Assessment and Definition of Capacity Development Strategies, conducted by ADD, March/April 2005

Ongoing Research:

Title: National Disability Survey in Afghanistan
Researchers: Jean Francois Trani and Parul Bakhshi commissioned by Handicap International
Started: Nov 2004 and End on Dec 2005.
Donors: EU, UNOPS, SDC and French Embassy
Dissemination strategies: Through UNDP/NPAD, European Commission, and Ministries

Appendix 8

Selected list of work on disability and development in Bangladesh and ongoing research

List of Research Done on Disability and Development

1. Disability in Bangladesh: A situation Analysis, The Danish Bilharziasis Laboratory for the World Bank and the People's Republic of Bangladesh (2004)

2. Water Supply and Sanitation Access and Use by Physically Disabled People, CRP & WEDC, Loughborough University, UK 2004 funded by DFID

3. A Micro Study of Disability in Jamalpur District: Feisal Hussain, Md. Shahidul Haque, and S. M. Mayeen Ahmed, SARPV (1995) commissioned by Action Aid Bangladesh

4. Socio Economic Condition of Lathyrsim Victims of Rajshahi and Kushtia District, Dr. Abdul Quader Bhyan, P.C. Sarker, 1984 commissioned by Swedish Free Church Aid

5. Disaster and Disability: A Look into the Situation of Ling term Disabled in Saturia: Atiur Rahman, M Shahidul Haque, M Abdus Salam, Rathindra Rathijit, (1991) commissioned by PRIP Trust

6. Situation of Persons with Disability at the time of Natural Disaster, CSID (1999) commissioned by Action Aid Bangladesh

7. Situation Analysis and Need Assessment of Street Children with Disabilities of Dhaka City, CSID (1999) commissioned by SCF Sweden

8. Possibilities of Integrating Street Children with Disabilities into Mainstream Development Services, CSID (2000) commissioned by SCF Sweden

9. Existing Situation and Opportunities of Employment of Persons with Disabilities in Bangladesh, Nirafat Anam, CSID (2002) commissioned by Action Aid Bangladesh

10. Situation Analysis of Women and Adolescent Girls with Disabilities of Bangladesh, CSID (2002) commissioned by Grameen Trust

11. Educating Children in Difficult Circumstances – Children with Disabilities, Noman Khan, Tarique Ahmed, CSID (2002) commissioned by ESTEEM Project, Govt. of Bangladesh

12. Good Practice on Inclusive Education in Bangladesh, CSID (2003) commissioned by UNICEF Regional Office, South Asia

13. The Situation and Prospect of the Use of Computers for Persons with Visually Impairment, CSID (2003) commissioned by Peace Corps, Norway

14. Together In Education – Promoting Education of Children with Disabilities through BRAC Non-formal Education Approach, CSID (2004) commissioned by BRAC

15. A Field Survey of Situation of Physically Handicapped Children in Bangladesh, Mia Allimullah, Islam Md. Hafizul & Ali, Md. Shamsher, Institute of Social Welfare and Research (ISWR), University of Dhaka 1979.

16. An Overview of Physically Disabled in Bangladesh, Akhter Tahmina, Institute of Social Welfare and Research, University of Dhaka, 1997

17. Family and Social Life of Disables, Mannan Bashira, ISWR, University of Dhaka, 1996

18. A Survey of the Disabled Children in Dhaka, Sobhan M.A. and Rahman, Mahnur, 1962

19. Impact of Sign Supported Bangla Language for Social Inclusion of Hearing Impaired Children, Sharmin, Iffat

20. Academic and Social Integration of Hearing Impaired Pupils into Mainstream Educational Setting, Ahsan Tariq, Institute of Education and Research(IER), University of Dhaka, 2000

Ongoing/Planned Research on Mainstreaming Disability in Development Cooperation

No. 1

Title of Research Stigma and Mental Illness in Cross National Perspective (SGC MHS)
Name of Researcher(s)/Agency/Other Q. K. Ahmed and Nilufar Banu of Bangladesh Unnayan Parishad (BUP) for Bangladesh part
Brief description of Research (Aims and objectives) To understand of problems of people with mental health, social attitude and the ways to overcome the situation
Where it is being done? It is a global research project including Bangladesh, coordinated by Indiana University, USA
Start date – End date Started in 2004; it will be ended in Bangladesh by 2005 but globally by 2007
Funders Bangladesh research part funded by Indiana University
Is it being done by/with disabled people or DPOs? It is not done by DPOs but disabled people especially the mentally ill people will be the audience and target of the research.
How does it relate to mainstreaming in development cooperation? It will be useful for mainstreaming. The problems of mental illness and social attitude will be identified.

Is there a dissemination strategy?
Global dissemination; it may be through publishing a book

No. 2

Title of Research:
Situation Analysis and Assessment of Education for Children with Disabilities   in Bangladesh, South Asia, East Asia and South Africa
Name of Researcher(s)/Agency/Other:
Centre for services and Information on Disability (CSID) in Collaboration with Overseas Development Group (ODG), University of East Anglia, UK. *List of Research Team members:* 1. Mr. Monsur Ahmed Choudhuri - Member   (Person with Blindness) 2. Mr. Khandaker Jahurul Alam   - Team Leader   (Person with Physical impairment) 3. Mr. Rabiul Hasan   - Member 4. Ms. Sayeda Asma Rashida   - Member
Brief description of Research (Aims and objectives):
The broad Objectives of the Research is: - To assess and analyse the shortfalls in the existing design and implementation process of education program for Children with Disabilities.   - To assess the effectiveness and impact of existing inclusive education programs in terms of attitude, enrollment, repetition and dropout.   - To assess the impact of special versus inclusive/ integrated education.   - To identify successful case study/examples from Africa, South and East Asia on inclusion of children and young people with Disabilities in to education system.   - To identify areas/issues and possible interventions for strengthening and promoting inclusive education including North-South Cooperation and Collaboration.
Where it is being done?
The country focus of the Research is Bangladesh, Nepal, Vietnam and South Africa.
Start date – End date:
17 January - 30 June 2005
Funders:
DFID through ODG, University of East Anglia, UK.
Is it being done by/with disabled people or DPOs?
Yes; Advocacy Group of Children with Disabilities involved directly with the Research as consultative committee. People with Disabilities are involved as Research Team members and collecting data from the field. DPOs are being consulted through FGD.

How does it relate to mainstreaming in development cooperation?
The Research would find out the ways and means of mainstreaming education of children with disabilities. The Research would also suggest the issues and interventions on development co-operation.
Is there a dissemination strategy?
CSID is conducting the Research on behalf of ODG, University of East Anglia, UK. As per condition of TOR - CSID has no right to disseminate or disclose any information of Research findings. It is depend upon the ODG - University of East Anglia how they would disseminate and use the findings. CSID would like to use the findings to advocate and convince Government and NGOs in mainstreaming the education issue of children with disabilities if ODG permit.

No. 3

Title of Research
Accessibility Study in Bangladesh: a. access to physical infrastructure and b. access to services: health, education and employment.
Name of Researcher(s)/Agency/Other
Salauddin Saibal, InterLife Bangaladesh (ILB) and Nazmul Bari Centre for Disability in Development (CDD)
Brief description of Research (Aims and objectives)
The general objective of the study is to survey the baseline situation of 'physical' and 'accessibility concerns beyond physical mobility' to the built environment and access to other basic services for people with disabilities in Bangladesh.
The study will make a thorough analysis of the current situation of accessibility that a person with disability encounters in every day life. The situation will intend to identify the overall state of 'physical accessibility' and 'accessibility beyond physical mobility' in Bangladesh. Accessibility provision for a person with disability will be considered in the study mechanism, which will include the following TWO broad areas:

a. 'Physical Accessibility', which includes, built environments of education, employment, information and basic services, policies related to built environments, professional education and professionals who are involved in planning and realizing built environments of transportation, education, information, health etc. Also review and recommendations on national and international policies, approaches, strategies, practices pertaining to physical accessibility etc.

b. 'Accessibility concerns beyond physical mobility' which includes environment access to all required basic needs services like education (learning environment), information, employment, basic services (healthcare including water and sanitation, transportation, housing, Government Bodies, Culture & Recreation). Also review and |

recommendations on national and international policies, approaches, strategies, practices etc.
Where it is being done?   The study data will be collected from representative samples of Bangladesh.
Start date – End date   April 1, 2005 - August 31, 2005
Funders   Handicap International supported by DFID-UK.
Is it being done by/with disabled people or DPOs?   Persons with disabilities are one of the prime sources of data of this research.
How does it relate to mainstreaming in development cooperation?   Accessibility is a concern for the whole society. Planning, design, construction, and maintenance of the environments are not only technical matters. They are also political and development issues. Accessibility is of special concern for policy- and decision-makers, legislators and planners, as well as funding agencies and government, non-government and private organisations involved in health, education, employment, recreation, sports, culture, water, sanitation and other development areas. Accessibility is also crucial when it comes to transportation and information and communications services.
Is there a dissemination strategy?   Handicap International & NFOWD

Appendix 9

Gap analysis report – Africa

SCOPE AND METHODOLOGY OF THE RESEARCH

Samaita Associates implemented and facilitated the research process in South Africa, Uganda, Zambia, Zimbabwe, Malawi and Lesotho. The scope of the research was limited to assessing gaps in research based on the perceptions of respondents, mainly people with disabilities and DPOs.

A questionnaire was used to obtain inputs and comments from individual and institution respondents. The questionnaire had open- ended questions. Additional questions were administered during research interviews.

In addition to government respondents, personnel of USAID and NORAD were interviewed. The questionnaires were analysed in order to get full understanding of perceptions of respondents on the topic.

FINDINGS

1 Understanding of Gaps in Research

Respondents were asked a question on what is being or will be researched in the field of disability and development cooperation.

In Uganda, respondents from DPOs were vaguely aware of current or past research in their respect fields. At times respondents referred to past evaluations or needs assessments and were not quite sure about differences between these terms.

The situation was the same in South Africa where respondents were generally unaware of disability research that had been or was currently being implemented.

Respondents were asked about gaps in research and the topics they would want to be researched, below we provide a comprehensive list of areas of research that were seen as essential. Based on the interviews that were carried out and emphasis by the respondents, we were able to rate the topics using a star system where a single star represents least important and a five star presents priority areas of research. In rating the research topics, we also considered the number of times the issues were raised by respondents.

It is clear that topics related to HIV/AIDS, poverty eradication, employment and development cooperation received a very high rating.

The low rating in some topics may be due to the rating criteria used. The proponents of these topics (e.g. rights of woman with disabilities and deafblindness) felt that their topics should be given top priority.

C.2 Research and Evidence Concerning the Rights of People with Disabilities.

Respondents had different views on what constitute human rights for people with disabilities. The general perception was that human rights and disability rights mean the same thing and that the latter specifically referred to:

- ❖ "fundamental entitlements to every human being
- ❖ a set of recognised ----- necessities
- ❖ Human rights are inalienable, God- given. Entitlements guaranteed by the Constitution and Bill of Rights.
- ❖ Rights a person has simply by being a human being.
- ❖ Owning property and means of production.
- ❖ Enjoyment of basic freedoms and liberties by any person.
- ❖ Everybody is equal before the law "nothing about us without us!"
- ❖ Access to medication

All respondents concurred with the view that persons with disability are entitled to human rights. They noted that people with disability are often denied their human rights, particularly in relation to education, employment, basic human

needs (marriage, childbearing and relationships) and other rights entrenched in national Constitutions/ Bill of Rights.

On whether there has been research to monitor outcomes of implementation processes, all respondents concurred that no such research has been implemented, with the exception of the ten-year review exercise conducted among national government departments in South Africa, where DPOs were not involved in the process.

To illustrate violations of human rights in Uganda and inability to collect evidence, one responded mentioned that:

- A young man was refused entry into a teacher training institution in the Tororo district of Uganda due to his disability.
- A disabled Councilor in Lira District (Northern Uganda) was 'deposed' on the grounds of disability and not being "flexible"

In Uganda, evidence has been collected on the needs of people with disability in agriculture. In addition an assessment was carried out to determine the impact of poverty on people with disability, the need for accessibility and development aid.

One respondent called for research and collection of evidence related to the experiences of people with disability in local government in Uganda (i.e. experience of elected councilors). A document on best practice entitled " Footprints in Social Transformation" has been prepared.

The role played by terminology in reinforcing negative attitudes against people with disability was also discussed during interviews. Words such as "Kasiru" (Luganda language) which means "stupid" are often used to describe deaf people in Uganda.

C. 3 CAPACITY TO RESEARCH

All respondents in Uganda and South Africa highlighted the fact that DPOs lack adequate capacity to conduct research. It was stated that very few disabled persons have research skills. There was a perception that where research is carried out by able-bodied researches, people with disability must actively involved in the design, implementation and monitoring, including the utilisation of the findings of such research.

There was a call for resources to build research capacity of people with disability and their organisations. The need for capacity was highlighted in other areas such as:

- Management
- Implementation teams that are trained and have adequate resources
- Office and programme infrastructure

Some respondents pointed out that unless people with disability get actively involved in implementing research their needs would not be addressed. Often research done for people with disability is based on "obvious facts" and is " moderate" with a bias towards professional approaches/ standards.

CONCLUSION

This report highlights the findings and issues raised by respondents during interviews on gaps in disability research. Twenty-five topics in the table below were identified by the people who participated in the research.

Different topics were viewed as top priority by different DPOs. However, there was consensus on topics related to poverty eradication, HIV/AIDS, access to human rights and development cooperation as a tool for resource-redistribution in favour of disability programmes.

E.   RECOMMENDATIONS

While identifying research gaps and topics was an easy task, defining priorities will be difficult given the research backlog that presently exists, the needs of different stakeholders and limited resources to conduct meaningful, needs oriented research. It is, however, possible to make a few general recommendations for future consideration:

1. Research principles such as those discussed at the Malawi Roundtable are a good starting point in guiding disability research.

2. It is essential that research capacity should be built among people with disability and their organisations.

3. Research should empower and enable people with disability to engage effectively in processes such as the PRSPs, policy development work, and setting up and mainstreaming of disability programmes and implementation processes/ studies.

4. Research within the realm of the social model on disability should be given top priority.

5. Programmes that utilise research findings are crucial if people with disability are to benefit from research.

JUNE 2005

Table 1

ANALYSIS OF GAPS IN RESEARCH: AFRICAN COUNTRIES

Topic

Star Rating

* Least priority
** Good to do, but not essential
*** Research in this area would be useful.
**** Very good area to conduct research.
***** Results will be very useful in our work
*****Top priority research area.

Research Topics	Number of stars
1. Inclusive education: issues related to access, assessment and effectively of policies	4
2. Accessibility of the built environment and services: the extent to which lack of accessibility hinders integration and effective service delivery.	4
3. Employment opportunities, barriers and related topics.	5
4. Impact of HIV/AIDs among disabled people including strategies for prevention and management.	4
5. Involvement of disabled people in agriculture	
6. Active participation and benefits from poverty alleviation strategies.	5
7. Understanding limitations and opportunities available to different categories of disability.	3
8. Impact of post-polio syndrome and rheumatic conditions on people with disabilities	2
9. Mainstreaming of disability programmes within government and private sector strategies.	3
10. Comparative analysis of North/South trends in order to inform policy planning and implementation processes.	3
11. Impact of 'social stigma' on people with disability	3
12. Causes, impact and effective management of HIV/AIDs among woman with disabilities and orphans.	4
13. Analysis of case studies on where active 'participation' of people with disabilities, particularly with reference to	4

woman, has occurred was participation effective? Where the desired results achieved?	4 5
14. Are advocacy and lobbying strategies of DPOs effective?	
15. Impact of poverty eradication programmes on disabled woman.	4
16. Baseline study on economic empowerment of people with disabilities	5
17. Baseline study of observance of human rights days for people with disabilities and particularly for disabled girls	4 3
18. What local government policies are needed to effectively integrate and mainstreaming the needs of people with disabilities?	4
19. Research to gather statistical data on prevalence of disability.	4
20. Do disable have sustainable livelihoods strategies? What options are there and to what extend are disabled people benefiting.	4
21. To what extent are woman with disability included in social, political and development programmes?	5
22. Are disabled people benefiting from PRSPs and debt relief? What strategies have worked in terms of integrating people with disability in poverty reduction/ debt relief strategies.	2
23. Need to analyse benefits of development cooperation to people with disability. Are fundraising strategies effective.	
24. With regards to blind people, there is need for research on human rights violations particularly in relation to blind people infected and affected by HIV/AIDS.	
25. Special needs of blind persons, particularly in relation to employ opportunities and universal primary education.	
26. Involvement / programmes of disabled people from war affected environments.	
27. Research on the number, and other statistics of deafblind people in each country. Assessing major causes of deafblindness and most suitable Communication models. How to prevent and establishing proper definition of deafblindness.	