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A.   Introduction

Lively debates took place during the past two-and-half weeks. Below we have attempted to summarise some of the issues that came up for discussion. We shall be posting the remaining issues that were discussed at the Malawi Round Table. Feel free to add value to these discussions.

Current discussions centred on research topics, disability charters, issues from the Malawi Round Table Discussions (MRTD). Concerning these issues, are there any additional thoughts that you may have generating since the Malawi round table discussions? Do you find disability charters as an effective method of advocacy and lobbying? What other advocacy methods have you used successfully in your country?

B.   Issues from the Malawi Roundtable

The moderator posted a message requesting e-forum members to contribute to the Malawi round table discussions. A number of responses were received from e-forum participants. Below, I have categorised the various responses according to specific themes:

B.1   Millennium Development Goals

Muhammad Hilaluddin, on behalf of Angikar Bangladesh, expressed heartiest congratulations to all the participants of the Malawi Round Table. He mentioned that Angikar Bangladesh had the following contributions to the discussions:

a.   The MDGs do not include the issues of disability rights and he felt that the inclusion of disability in the MGDs should be the most important focus of the Malawi Roundtable.

b.   He mentioned that the pace of progress in '---implementing the MDGs in the vulnerable econo-geographic locations including Bangladesh is simply discouraging. The time-frame is sure to fail in all the sectors. The Malawi (roundtable) must investigate the reasons and place a viable corrective proposal stressing the urgent measures.'

c.   Transforming the society at large around inclusion of disability-issues '-- has been a quite challenging job for all the rights and development practitioners all over the globe. Mainstreaming the disability issues in the rights and development processes is of utmost importance for the relevant practitioners. Words must be translated into deeds.'

d.   In Bangladesh, the disability issues have been occupying increasing space progressively. Still the reflections in the print and electronic media do not correspond. Campaigns both inside and outside the media need to be strengthened in Bangladesh and elsewhere. The word 'civilization' cannot be meaningful unless it addresses the issues of disability with a deep sense of commitment.

B.2   Proceedings of Day 1: Malawi Round Table

The Moderator posted a message on the proceedings of day one of the Malawi Roundtable Discussions. The message covered the following elements:

♦ The successful Opening Ceremony with the Principal Secretary from the Ministry of Social Development and Persons with Disability.
♦ Expectations of participants on a very wide range of issues related to poverty and the MDGs.
♦ Lively discussion on the Millennium Development Goals and what they meant to participants who had very different experiences and opinions on their relevance and how best they could reflect the disability agenda.
♦ The practical challenges of engaging decision makers in disability issues based on the experience of participants. These ranged from securing funding and finding a voice, to finding ways to make disabled people more confident and developing the disability movement in Africa.

The following questions were posed:

What are the key areas for research in disability according to your experience?
How do we ensure the outcomes of research benefit the implementation of policies and programmes?

B.3 Day 2 of the Malawi Round Table Discussions

Day began by addressing the challenges of engaging decision makers on disability issues, but this time trying to find the ways to address the challenges.

The participants shared experiences of their projects and discussed the differences between countries. Examples of experiences included; networking projects in Malawi, raising awareness campaigns in Zimbabwe, lobbying groups for parliament in Uganda, and ways to improve the transparency of managing funds.

Building the capacity of DPOs came out clearly as a cross-cutting strategy to address many of the challenges identified. The stronger a DPO the higher the chances they have to influence decision makers – from a teacher or a parent right up to Kofi Annan!

The groups went on to determine the links between their work and the MDGs. The surprising discovery was that there were many more links than people realised, and already much was being done without people realising the significance of their work to the MDGs.

In the afternoon the group visited the Lilongwe Vocational Training Centre. The centre provides courses for Malawi disabled people in many disciplines including tailoring, carpentry, and accountancy. It is impressive that the Centre manages to run solely on donor money, but the group wondered whether there were ways for it to extend its funding strategy.

The afternoon of day two concluded with comments from the group on a series of presentations including:

• **DFID and disability.** The group raised concerns that DFID had not mainstreamed disability. This was significant because DFID are an important leader in the development field. The participants were encouraged that DFID were supporting individual projects.

- **The Seeing in the Dark advocacy project**. Participants were enthused by the work in Bangladesh, and had ideas about including such a demonstration project in the next two roundtables.
- **The UN Convention**. This presentation gave the group an idea of its context, its relevance to DPOs and tips on how to engage with the process. The main message was: **"Don't wait to be invited – get involved"**. The following website has more information: www.un.org/esa/soc.dev/enable/rights
- **The Uganda PRSP**. This looked at the successes of NUDIPU in addressing disability within Uganda's PRSP. It was an excellent example to the group.

The question posed for Day two invited comments for the day's proceedings; on the research topics in the field of disability and how to prioritise suggested topics.

The Moderator posted a message concerning research topics discussed at the Malawi Round Table Discussions. On the subject of research topics relevant to the situation of disabled people in the developing countries, participants at the Malawi Round Table came up with a very inclusive list. In addition, guiding principles for research were also proposed.

The key questions that were posed requested e-forum members to comment on the propose guiding principles; provide additional topics for research and to prioritise research topics.

The guiding principles discussed at the Malawi Round Table Discussions were that 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 thorough and analytical
· Be specific and focused
· Be action oriented
· Have a clear plan for dissemination and utilisation (funded from the research budget)
· Be gender sensitive

Ten priority areas for research and related research questions were identified, along with a miscellaneous group of research questions. These are listed below:

1. Poverty and disability

How disabled people can engage in the PRSP processes

2. Legislation and policy

· What is the role of disability legislation and policies?
· What has the impact of securing legislation and policies? This should look at case studies of the role that the disability movement played in securing legislation and policy.
· What has been the impact of legislation and policy on the disability movement? 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.

3. Development aid and DPOs
· 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.

4. 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 KaR programme's research).

5. Prevention of disability

· What role can DPOs play meaningfully 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?

6. Education

· 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?

7. 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?

8. HIV/AIDS
· 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?

9. DPOs

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

10. Transport

· What are the transport barriers faced by disabled people in their daily lives (survey and report)?

11. 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

C.   Inputs from E-forum Members

Muhammad Hilaluddin contributed on possible ideas for research in Bangladesh which included analysing the situation of persons with disabilities during disaster and voters rights and the role of the persons with disabilities.

He mentioned that this would result in special, appropriate and adequate measures being taken for the persons with disabilities during future disasters like flood, hurricane. He also felt that through voting, persons with disabilities will be able to exercise their democratic rights progressively.

Indumathi Rao there is a need to have studies to assist policy makers to develop evidence based policy planning in the following areas - CBR, Inclusive education, Portage, Micro credit, Self help groups, role of IT in rehabilitation, human resource development especially for CBR and Inclusive education and database developed.

In addition, the following were identified as possible research topics:

1. Disability rights charters and its impact in order to assist self help organizations to use the good practices across the globe.
2. Studies to critically analyze to what extent policies are translated into action.
3. Research on gender equity issues in programs meant for persons with disabilities.
4. Research to develop disability index by UN organizations
5. Studies to see how special needs of children below 3 years are addressed
6. Research on ageing and disability to understand what additional strategies and financial resources are required to include them in CBR
7. Research on appropriate dynamic definitions of disability such as educational definition, development definition, medical definition etc

Stefan Lorenzkowski mentioned that the research priorities are sensible and important. He added the need to explore ways of mutual learning and ways of information sharing at international level.

Sally Hartley has an important point on whether some of the topics are researchable. She advised that to answer this question one requires '--identification of a possible research design and methodology and establishing where in the world this could be undertaken in terms of access to the relevant population (and if a quantitative study) sufficient numbers of this population to make a worthwhile and statistical statement and also a location where there is a research infra-structure that can support and develop the

research programme. (It is wise to note that this is not often achievable within the framework of a service provider).'

She further suggested that we need to examine the list and divide it firstly into whether we felt that the questions asked are focused enough, and if not how they can be focused down; what methodology would be appropriate; and what kind of sample do we require and where to get this. What research establishments are available to you?

D.   Disability Charters

Another topic that came under discussion was that of disability charters. **Indumathi Rao** presented on the topic: **'how to set up DISABILITY CHARTERS-Guidelines'.**

Indumathi Rao mentioned that charters are self and group Advocacy Forums, Activist groups, and clubs belonging to an organization having similar interests. The chartered organizations consist of community organizations, Self help groups/ or group of interested citizens with disability or families with a member with disability, which is chartered at the State level and national level.

The objectives of the charters could be to:

1. Create an awareness on the rights, strengths and opportunities for persons with disabilities in the society

2. Promote a positive image about people with disabilities in the society

3. Eradicate myths, misconceptions, wrong notions, about disability

4. Promote self help mutual aid groups of stakeholders, to meet the individual and group needs

5. Collect and disseminate information concerning people with disability.

6. Network with other charters, NGOs, PRIs, and other civil societies

Examples of different sectoral charters were given as follows:

1. Prevention and early intervention charter for families of a person with disability

2. Educational rights charter for families and children with disability

3. Vocational training and employment/work opportunities charter for persons with disabilities

4. Charter for rights of women with disabilities

5. Charter for senior citizens with disabilities

6. Charter for human rights protection of persons with disabilities

Gladys Charowa gave input on the issue of charters. She mentioned that it was a very noble idea to have such charters and wondered how these structures would be funded in

developing countries, such as Zimbabwe. She highlighted that the attitudes of stakeholders towards disabilities, was that of regarding people with disabilities as useless and a burden to them. People with disabilities are thought of in terms of handouts. She also mentioned that if the money for these charters was to be made available through government channels, it would not reach the intended beneficiaries.

She proposed an approach that includes first raising awareness among the stakeholders especially government for them to understand and accept disabilities. They must first change their attitudes towards disabilities.

Indumathi Rao mentioned that she was aware of the difficulty in finding resources for starting charters. However, she mentioned that it is necessary for persons with disabilities to have full control on their lives. Charters need skill development for advocacy in a systematic way. Perhaps some international donors could focus on supporting the charters. Each country needs to evolve its own the charter operational strategies.

Muhammad Hilaluddin the idea of Charters and mentioned that Angikar Bangladesh works in mainstream rights arena with a bias towards creating awareness within the mainstream HR movement in Bangladesh on disability rights. He mentioned that '--- before entering into 'disabilitykar' group, before getting in touch with the eminent disability rights practitioners including Indumathi Rao, we could not imagine the sphere, spread and depth of the endeavours. We are really enthused. We like to go further on the track of disability rights issues.'

Muhammad Hilaluddin requested for assistance, with strategic planning, technical aspects/ expertise, training and ways and means of fundraising. Furthermore, he requested for advice on translating issues related to rights into reality, and internship opportunities.

He wrote: "Our desire and determination, our commitment (ANGIKAR) are very much there. Please show us the path you have traversed, please enlighten us with your experiences, intimate us with your achievements, the odds, and difficulties you have been confronting while addressing the challenges."

In response, **Indumathi Rao** mentioned that they would be able to help in developing data base. She requested **Muhammad Hilaluddin** to send excel sheets of general population census and any surveys conducted by NGO's on disability for comparative analysis. "It is a pleasure to help you to set up disability rights charters."

Stefan Lorenzkowski brought to the attention of the group to the project Share-See (Self Help and Advocacy for Rights and Equal opportunities in South East Europe): http://www.share-see.org/about.htm. It is a consortium of DPOs and NGOs to fight for inclusion of all people into society.

E.   Other Topics Discussed and Resources Shared

The other topics that were discussed are:

- **International day of Persons with Disabilities-for public dissemination** by **Indumathi Rao**
- **Cost of Insulin and Diabetic Disability** by **Muhammad Hilaluddin**

Two publications of CBR NETWORK ready for distribution are:

- **Equity to women with Disabilities-National consultation Report**
- **Right to equity-A Comprehensive Data base on Disability in India**

Another publication is also available: CBR RESOURCE KIT-2004 UPDATE (CBR Future solutions now). CBR resource kit which contains 52 CD's with virtual lectures, well equipped digital library, CBR software for assessment, planning tools, multi media etc.

A new resource has been shared in the resource section of Disability KaR - disability and development by Niki Maniam.
Title: HIV/AIDS and disability
Description: This list may also be of interest; it focuses on disability and HIV/AIDS and pulls together a wide range of resources. If anyone finds it useful please do let the group know.

If you have any other resources to share with the group please add them to the resources section. External URL:
http://www.ids.ac.uk/sourcesearch/cf/bsubjectdirectory.cfm?No=sd&display=basic&Search=QL_hivdis_AS04&title=HIV%2FAIDS%20%26%20disability

F.   CONCLUSION

Thank you all for your contributions. Again to other members of the group that have not yet contributed-please post your contributions to the current and future topics.

Thank you all!