UPDATED REPORT AS AT 1 NOVEMBER 2004

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A. Introduction

This report outlines the activities on the e-forum to date starting with the most recent postings and submission. Contributions from members of the e-forum are briefly analysed with additional questions and comments in order to guide the discussion process.

Members of the e-group should feel free to add comments and refer to the main submissions and postings on the website for additional information.

B. Disability and the Millennium Development Goals (MDGs)

This topic generated a great deal of discussion on the e-forum. The moderator posted key questions and additional information on the MDGs.

Gladys Charowa mentioned that the topic of Disability and the Millennium Development Goals (MDGs) is a serious issue to tackle and the MDGs cannot be achieved if people with disabilities are not included in all development processes. She felt that the 10% of any population is disabled people is an underestimate. People with disabilities are more than that taking into account that in most cases people with disabilities are being kept indoors as they feel ashamed of them. Also, the issue of HIV/AIDS leaving many people disabled is not being taken into account.

The MDGs are relevant to people with disabilities if the people with disabilities are included in all the programmes from local to international levels. Gladys felt that the problem is that these goals are being set without taking into consideration people with disabilities.

In Zimbabwe, it is not clear whether any programmes exist regarding MDGs. Gladys pointed out that most of people with disabilities live in absolute poverty. They are not involved in Poverty Reduction Strategies as they are viewed as useless people at the same time they are not given the opportunity to contribute into the country’s economy. This has negative implementations for the country and the individuals.

The disability grants of Z$10 000,00 being given to some people with disabilities in Zimbabwe is not even enough to cover one transport cost to go to the Social Welfare office to collect it. What it means government’s intervention of the so-called grant is not contributing to the welfare of people with disabilities.

There was a call for the e-forum to come up with strategies which could be used to contribute to the MDGs for the benefit of people with disabilities worldwide.

Indumathi Rao, Regional Advisor for CBR Network (South Asia) mentioned that in South East Asia, the ‘goals (look) like stars and moon up in the sky.’ He noted that previous slogans like ‘Education for ALL, Health for All, hunger free society are mere slogans’ which have largely ‘failed to move beyond mere catchy slogans’.

Have these catchy slogans worked in your country?
Indumathi Rao mentioned that the main reasons for the failure of these catchy slogans are that they need to be supported by policy makers with good political will. In the context of South East Asia, he highlighted the need separate ministries, allocated with adequate funding, and that adopt inclusive strategies in poverty reduction.

How can the MDGs be successfully implemented in your region or country? Has the government allocated any funding for the implementation of the MDGs? Are disability programmes included in fiscal/budget plans for your government?

Indumathi Rao also questioned the perception that strategies such as Micro-credit are a panacea for Poorest of the Poor. He noted that some credit programs foster group formation and enable women to generate income, thus offering potential for both political and economic empowerment. However, due to the fact that credit by itself cannot overcome patriarchal systems / social stigma, negative attitude towards poorest people such as people with disabilities, aged persons, women from lowest rung of the society, this potential is not always realized.

The poorest people also ‘fear’ to venture into income generation, which comes from factors not related to money, according to Indumathi Rao. The factors that contribute to this fear are:

- The structural adjustment policies that help create a burgeoning informal sector by destroying small enterprises, farms and formal-sector jobs also undermine the potential for income generation in that sector.
- The cumulative effect of rising costs, declining demand, and competition from both cheap imports and increased entrants into the sector leads to shrinking profits in informal-sector trade.
- The current wave of euphoria over micro credit misses the salient question: Since a majority of poorest and disadvantaged people has neither the skills nor the inclination to be entrepreneurs, why are micro enterprises proliferating?

The Zimbabwe Parents of Handicapped Children Association (ZPHCA) in Bulawayo concurred with the view that the MDGs will never be met if the exclusion of people with disabilities and other minority groups continues. The ZPHCA mentioned that in Zimbabwe

‘---we are luck to have a diverse and strong Disability movement in terms of number of DPOs. There is a disability board that is given a budget for the benefit of people with disabilities. This year it received a good amount from government. They went around informing DPOs and members of how it is to be used. The issue is (whether) DPOs (are) utilising this facility? If so how?’

It was noted that the Disability Act itself needs a lot of home work due to the fact that it has discrepancies and ‘implementation is still far from reality, they are mostly paper policies.’

The policies that are there do not mention or include people with disabilities as a special category (i.e. they do not cater for their special needs.)

Christine Cornick mentioned that one of the challenges with the MDGs in relation to disabled people is in relation to the number one goal: Eradicate extreme poverty and
hunger, with 2015 as the target for halving the proportion of people living on less than a dollar a day and those who suffer from hunger. It is acknowledged that disabled people are amongst the poorest of the poor.

Efforts to lift people from poverty may well focus on those who are ‘easiest’ to lift from poverty in an effort to deliver the numbers, and disabled people are likely to be more challenging to lift from poverty than many non-disabled people. Therefore without a specific Millennium Development Goals related to disability, the danger is that disabled people are once again marginalised in these efforts, particularly when they are not consulted in the development of poverty reduction strategies.

It is important to ensure that disabled people are represented in the development of strategies for poverty reduction at a national level, and that is something we can all lobby for through our work.

C. Disability and Poverty

The relationship between disability and poverty came under discussion. Most people with disabilities live in the economically poorer countries of the South where lack of access to human rights is first and foremost about the right to life, to food, water, and shelter.

Because poverty is both a cause and consequence of disability, WHO estimates that as many as 1 in 10 poor people are disabled. Yet within development co-operation policy and practice aiming at poverty reduction, people with disabilities usually remain invisible and excluded.

The relationship between disability and poverty has been clearly established. While the risk of impairment is much greater for the poverty-stricken, the converse is also true. The birth of an impaired child or the occurrence of disability in the family, often places heavy demands on the limited resources of the family and strains on its morale, thus thrusting it deeper into poverty. The combined effect of these factors results in higher proportions of disabled persons among the poorest strata of society in the developing countries.

The main questions posted were:

- What are the links between poverty and disability?
- Does poverty cause disability and vice versa?
- Realistically, is it possible to break the poverty cycle? In what ways and using what methods?
- Does the same definition of poverty apply to different sections of a country’s population? Feel free to provide your own understanding of what poverty is and what are its characteristics according to your experience.
- What do you feel about the impact of the poverty reduction strategies that are being developed in your country in terms of disability inclusion? What are the suggestions for effective interventions?

Gladys Charowa gave a detailed analysis of the situation in Zimbabwe proving a very good insight of some of the key causes of poverty in that country. Her article raised key important issues:
1. A government that passes legislation that is not effectively implemented. The question is: Where implementable regulations formulated to back up this legislation?
2. The issue of the relationship between poverty and the different disability groups was very interesting. The Moderator checked with other members whether disability affect different disabilities in different ways?
3. Gladys wrote that "...Spinal Cord Injury is the most complicated disability and many people do not know about it. People with Spinal Cord Injuries are being excluded in many issues which affects people with disabilities. Most people such look at physical disabilities without knowing that spinal cord injury people loose feeling and sensation hence they are unable to control their bowels and bladders."
4. Gladys wrote that 'Disability is more serious for women'. The Moderator checked with members of the e-group whether this was their experience in their respective countries? What are the traditional practices related to the girl child? For instance, was the practice of 'swapping' the girl child still prevalent in their society? What about practices were girls are circumcised (mutilated) or other rituals? Is it true that girl foetuses are being killed before birth in some countries in order to reduce the population?
5. Gladys highlighted the fact that disabled people are treated as being 'useless, a burden...'. Have you experience this in your countries?
6. The issue of natural disasters, droughts, typhoons, etc came up for discussion. The Moderator asked the following questions: What can we do to support each other as disabled people in such circumstances? How can we help each other deal with harsh economic realities in our countries? How can we help Zimbabwe, particularly, given the difficult political environment in that country?
7. Gladys specifically requested information on what Disabled People's Organisations are doing for their members. The Moderator asked members of the group whether they felt that their organisations were doing enough for their members.

Gladys challenged the forum to think in terms of 'strategies' to end these problems. What strategies do you recommend?

The issue of HIV/ AIDS came up for discussion. Irene felt that Gladys’ input brought out ‘a lot of issues to light, it is very similar to one (I) wrote about Poverty disability and HIV and Aids. Irene concurred that women ‘are in difficult circumstances.’ Alison Sizer and Gladys Charowa requested for a summary of the report on disability and HIV/AIDS which was subsequently posted on the e-forum. Irene clarified that the report was a result of a rapid assessment that was done in Bulawayo

In response to Irene’s inputs and report, Gladys Charowa asked whether ‘married women are have outside marriage sex affairs to prove that they are not to blame for having a disabled child or its the man who goes out for another woman while the mother is caring for the disabled child.’

In her experience, Gladys discovered that ‘most women are divorced when they have disabled children and they end up looking for the children on their own. Just because they do not have an income they end out into prostitution to get money to feed the disabled child, hence exposed to HIV/AIDS. At the end of the day they will leave the disabled children in the care of grandparents who are unable to take care of the disabled children.’
Gladys also mentioned that the disabled girl child is at risk of being abused by the able-bodied relatives and community at large being it physically or sexually. At the end, women and girl children are more exposed to HIV/AIDS than their men counterparts.

The question raised by the Moderator focussed on the following: What programmes are in place to assist? Are prevention messages reaching disabled people? In Braille? Through Sign Languages? Is sex and sexuality an issue that is freely discussed between parents and their disabled children? In fact, do parents of disabled children know about their children's sex and sexuality issues?

On the issue of policy, Gladys Charowa noted that more needs to be done to include people with disabilities in all HIV/AIDS and other programmes which affect everyone in society. HIV/AIDS organisations need to be sensitised by people living with disabilities and DPOs so that they can include them in their programmes. There is need to educate these organisations about disabled people’s needs and tell them that people with disabilities also have the right to sex.

Disabled youth should also have the right to sex. Gladys mentioned that ‘This is one area, where children with disabilities are not allowed to be engaged into sex life even through they are old enough e.g. over 25 years. Even the mothers with children with disabilities do not want their disabled children to be married or to have children as they think it will be a double burden for them.’

Gladys felt that ‘these children should be given their right to sex’ and she gave an example of her aunt ‘ who is mentally challenged. The parents did not want her to get married to a man who ended up giving her a child. The child is now a grown up and has taken care of her mother who is mentally challenged. I think we need to look at some of these issues more seriously either case by case. This is an issue for discussion. Any comments and viewed are welcome.’

Veronica Nakyewe from Youth Disabilities Development Forum (YDDF) wrote on the topic ‘Youth with Disabilities and Poverty’. She mentioned that there is a need for the different actors in Disability work to strength the role of youth with Disabilities as civil society actors and to enable youth with disabilities to organise and take action, in particular in connection with decentralised co-operation on poverty eradication and social cohesion. There was a need ‘to identify educational principles to promote global citizenship of young people Africa and in the world.’

Veronica noted that ‘there has been growing recognition in the last decade of the need for civil society involvement in development processes. More recently, there is a clearer understanding that civil society is diverse, and that capacity building with particular sectors of civil society is required in order for these sectors to fully shape, participate in, and benefit from the development (processes)’.

Fredrick Ouko was interested in the youth summit and requested for more information. Frederick is from Kenya Disabled Action Network, focussing on youth with disabilities.

She enquired as to whether people with psychosocial disabilities actively involved in the disability movement in Africa? Where are their human rights?
On the issue of women the Zimbabwe Parents of Handicapped Children Association (ZPHCA) agreed with the point that society perceives people with disabilities as a burden and useless. This did not, however, mean that there are no changes to attitudes. The organisation had experienced cases where parents ‘especially men (at times Women) abandon their children and wives (husbands)’ after failing to cope with the disability of a child. Killing of disabled children was no longer practiced in Zimbabwe but children are ‘excluded from society activities’ meaning that they are not regarded as useful.

Society even expects people with disabilities not to enjoy certain rights e.g right to have sex, marriage, and children. A lot of awareness and education is required to change these attitudes.

The ZPHCA noted that women are most affected, and ‘---because they are women; they take all the toil of women; and disability enhances this. The Adam/ Eve issue still goes on today, any problem in the home is blamed on the woman, and all success goes to men. This is so especially if the problems and failure are related to the girl child.’

During a ZPHCA survey, the organisation came across issues that support the theory that disabled are disadvantaged.

In trying to develop solutions, the ZPHCA proposes that people with disabilities can help themselves by advocating and lobbying for their rights. The ZPHCA has used complementary themes during awareness campaigns. Examples are "towards a barrier free world" advocating for the removal of all barriers and in order to ensure an inclusive and friendly world.

Trying to achieve equalisation of opportunities by removing barriers ‘but that alone is not enough, we have to network with others’

"Mainstreaming disability into all development work" and creating synergies between government and DPO programmes. DPOs should also take aboard other developmental issues e.g. gender, orphan care, poverty reduction HIV/AIDS, etc alongside direct disability issues and all developmental programmes should mainstream disability.

‘Let people with disabilities be part of these programmes, at all levels and in all sectors. Programmes should ensure that they address their special needs and create a situation where they benefit and are no barriers.’

D. Other Contributions

Other contributions are provided below in order to update members of the group. Note that some of the articles do not necessarily refer to the topics under review.

Kristina Scotland wrote on the work of The Wheels of Change campaign which is being launched by international development charity World Emergency Relief (WER) in order to highlight the plight of disabled peopled living and working within developing countries. Visit www.wer-uk.org

Indumathi Rao mentioned that a comprehensive data base is the prerequisite in planning rehabilitation programmes. Most countries in the world lack a data base on prevalence of
Our studies have shown disability identification needs skilled personnel and large scale census on disability require huge costs and in the (absence) of trained personnel such database are not reliable. The studies have also shown it is possible to develop a data base on disability based on the actual population census data.’ He provided the title of their publication “Right to equity-A comprehensive Data Base on Disability in India”.

The contributions below were made prior to the announcement of the topics under discussion. The Moderator’s comments are below some of the postings.

Ferdrick Ouko from Kenya Disabled Action Network wrote:

‘Being a youth with disability, it is only fair that I participate in discussions that are meant to uplift the plight of my fellow young disabled persons across (the) world’

Yes we agree with this position. Feel free to focus on issues that cause and/or exacerbate poverty. Questions for consideration and discussion:

What strategies are needed to address these issues? Families play a major role in shaping our youth in terms of values, and attitude to work/life, education, vocational training, and quality of life. Is our educational and training system equipped to provide skills that are necessary to reduce the impact of the poverty cycle or to enable youth to effectively fight poverty? What about the education, well being, and empowerment of disabled girls? Are they given the same treatment within families in terms of education and training? Do we discuss sex and sexuality within our families? Is AIDS/ HIV also affecting youth in your communities? How does this exacerbate poverty?

Elhadi Abdo from the Sudanese Society for Care and Rehabilitation of the Handicapped-Port Sudan city wrote:

‘I hope to catch up ‘with’ this event, other wise I will (receive) your prompt respond’

Welcome to the discussion group. News coverage on Sudan has mainly been on the conflict in Durfur region. How are disabled people fairing? Are disabled people seen as a priority in terms of food distribution, policy formulation, and general access to essential services? Are there stories of disabled people who have succeeded in life and in what they do? What opportunities are there for disabled people?

Hilaluddin Muhammad of Angikar Bangladesh Foundation in Bangladesh wrote:

‘Enable the disabled thinking about the disability issues.’

We take it you mean that disabled people must be in forefront of their own development and fight for human rights? Yes we agree that disabled people should be in the forefront of their own development. Bear in mind that we need support and government should be
playing an active role in creating an environment that enables disabled people to fight poverty. Or can we do it on our own?

The issue to raise here is whether it is possible to achieve positive results (in terms of poverty reduction) if our struggle is fought on our behalf by other people? If so, who should we entrust with this responsibility and what will be our role in the process?

Ekaete Judith Umoh of Family-Centered Initiative for Challenged Persons (FACICP) in Nigeria wrote:

‘I think the topic for (discussion) is well selected and very timely, as it would (further) share more light on the social model of disability theory, and it would help us understand better that the issue of persons with disability is a development issue.’

Your contribution introduced a very important argument, that disability is a development issue and, if we may add, not a welfare issue. How can we ensure that disability issues are properly aligned to development priorities? How can we advocate for disability issues to be included in government programmes that promote development? Will promotion of development necessarily result in poverty reduction among disabled people?

Even more important, if our advocacy work fails to achieve results, what should we as leaders, activists and individuals do to effect change? Should we develop more radical tactics (throwing stones at government building, sit-in demonstration, hostage taking, toyi-toying (a South African term which refers to street demonstrations), and/or other means (someone in one of my workshops mentioned ‘armed struggle’). Are radical tactics effective? Are there alternatives to radicalism?

Anele Madziakapita from Forest Town Foundation in South Africa wrote:

‘I am currently working as a Fundraiser for Forest Town Foundation that supports Forest Town School for the disabled and other 40 caregiving centers in Gauteng, South Africa. I am interested to attend because I would like to carry out a research on ”Development and the Disabled” for my Masters Degree with the University of South Africa. I might bring a bit of experience from the school that I fundraise for and the centers that I visit and monitor. I expect to get a lot of information necessary for my research and for the proposal writings that I do in Fundraising. I also believe this will help me in my future (career) as I am interested to work with the disabled in development programmes. I plan to find my own transport, ‘accommodation’ and all the necessary costs involved. Please give me a chance to participate in this roundtable e-forum.’

Let us concentrate on the issue of research as a tool for generating knowledge that enhances our fight against poverty. Issues that need further debate are whether disabled people are being ‘over-researched’? Who should do disability research? Academics or disabled people themselves?

Can we honestly say that we have adequate information, knowledge, and statistics to facilitate effective planning of anti-poverty programmes that improve the lives and well-being of disabled people?
Is development cooperation enhancing the lives of disabled people in developing countries? What has been your experience of working with funding agencies? Should we be looking more at the international fundraising market or internally within our countries? Should we feel guilty for accepting development aid?

Indumathi Rao from CBR NETWORK (SOUTH ASIA) India wrote:

‘I am (interested) in disability rights charters’

An issue here is to try and identify the various means that we can use to lobby and advocate effectively. Lobby and advocate for what? What are trying to achieve with our advocacy work? Our rights? A re-distribution of resources (by the state, private sector, aid organisations, etc) in favour of development programmes that benefit disabled people?

Is re-distribution of resources an achievable objective? How can we influence our countries to spend less on the military and war effort and more on development programmes? Would this help us to achieve our anti-poverty goals?

Jonathan Solomon from Care and Support Services Consultant: Special Educationist/Therapist, Sri Lanka wrote:

‘Serving People with Special Needs, brings meaning to my life.’

A very powerful statement! Let us try to focus on the role of professional service providers in poverty alleviation. What is the role of Disabled People’s Organisations with regard to the fight for disability rights? What is the correct balance between service provision and rights?

Does the current training of professional service providers give them skills to contribute to poverty reduction goals?

Nafees Rahman of NFOWD in Bangladesh wrote:

‘I believe this will be a great opportunity to learn about disability and poverty, and the interrelationship’

Yes, we agree.

Tinh Tran Van VVAF Vietnam Viet Nam wrote:
‘More friends less enemies’

Would this perhaps increase our chances of concentrating more on positive aspects of life such as peace and security? Are these essential requisites for poverty reduction?

Veronica Nakyewe from Youth with disabilities Development Forum in Uganda wrote:

‘Informative Educative and interest which (l) real desire’

We look forward to your contribution.

Thank you all for your contributions. We trust that the questions raised above have helped us to focus a little bit more on the subject under discussion: the link between disability and poverty. In your contributions and responses to the questions above, let us try to identify, analyse, and debate this linkage, its characteristics, and how we can contribute to change.

E. Resources Available:

- A new resource has been shared in the resource section of Disability KaR - disability and development by Nici 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

- Indumathi Rao provided the title of their publication ‘CBR RESOURCE KIT-2004 UPDATE’ (CBR Future solutions now). Engineer Muhammad Hilaluddin, Chief Director from Bangladesh requested for a copy of ‘RIGHT TO EQUITY’.

- Indumathi Rao provided the title of their publication Asiatic Tele Health - A new service for health, rural development, and rehabilitation workers.

F. CONCLUSION

Thank you all for your contributions. We will keep you informed about proceedings at the Malawi Round Table Discussions and please feel to contribute to the discussions through the e-forum. We will make sure that your contribution is reported to the round table.

To other members of the group that have not yet contributed—please post your contributions to the current and future topics.

Thank you all!