

'MAINSREAMING DISABILITY IN DEVELOPMENT'
(Midterm report of E-forum discussion
for Round Table-II as on February 24,05)

Sponsored by
Healthlink Worldwide (UK)
&
Organized by
Blind People's Association, India (BPA)
(as part of the Disability Knowledge and Research(KaR) Programme
during February 1- March 28, 2005)

Guidance

Dr. Bhushan Punani
Executive Director,
Blind People's Association(India)

Niki Maniam
Web Communcation Coordinator
Healthlink Worldwide (UK)

Moderator :-
PRAMOD KUMAR GUPTA
Honorary Coordinator,
Blind People's Association,
Surdas Marg, Vastrapur,
Ahmedabad-380015 (Gujarat) India.
Telephone- 0091 79 26304070
E-mail- pramodkumargupta27@yahoo.co.in

1. Introduction

E-forum, a flow, which is passing through three RT's with various interlinked topics. Group started with a theme "**DISABILITY, POVERTY AND MILLENNIUM DEVELOPMENT GOALS**" around the first round table in Malawi. **RT-I** showed the way to more inclusive society by interlinking the Disability issues with MDGs. In RT-I, it was clearly shown that disability issues are interrelated to any other issues and should be considered in that way only. Obviously for RT-II, the main theme emerged was 'Mainstreaming Disability in Development'. The aim of the roundtable discussion is to explore how to mainstream disability in development, providing an arena for reflection on, sharing of and learning from experience. This roundtable is focusing on planning for mainstreaming in development (a "how to" discussion). The roundtable will provide an opportunity for decision-makers to learn from and hear the views and experiences of people with disabilities, disabled people's organisations, and institutions working on disability in the South, bridging the communication gap between stakeholders at the grassroots level and policy makers.

2. WHY MAINSTREAMING?

Group discussion was started with first posting with the invitation for the discussion on the topic of "why" to promote inclusion. Few questions were also given, so that discussion can evolve around. Members were invited to share their views about-

- Do you think that mainstreaming disability is an effective way to create a-
-barrier-free,
-rights-based
-inclusive society for people with disabilities?
- Does mainstreaming disability help governments to engage with the needs of people with disabilities?
- Can legislation really force organisations to mainstream disability?

3. DEFINING MAINSTREAMING

Very interestingly, few of the postings very nicely elaborate the term 'Inclusion' or 'Mainstreaming'. It gave a deeper understanding to the thought process among the group. Some of the members were not clear about the term in its fullest. For some it was like learning the thing again. So, it helped everybody to get an insight. Now, let us define Mainstreaming-

- One comment from the e-forum was that "in answer to the question whether mainstreaming disability is an effective way to create a barrier-free, rights based society for people with disabilities I would bring the discussion to the question of attitudes. I would say that "Mainstreaming is a good way of bringing a change in the attitudes of the society and therefore leading to an inclusive society"
- "Inclusion as something which benefits everyone, rather than simply as a rights issue"
- "Inclusion is for life- different needs at different ages- so has to work on multiple levels as working with people of different ages"

- “Inclusion means Convergence means having place for all (including disabled ones) at all places”
- “Mainstreaming disability means that all policies, programmes and projects should include disability as a key issue”
- “Inclusion is based on the principle ‘every individual is unique’. The goal of inclusion is to facilitate an environment in which no one feel left out because of individual different”
- “The sound foundation on which one need to think and plan inclusion is to recognize and celebrate this diversity opening a way of life each one works towards actualization of potential that is inherent in every individual”

- **The three dimension of inclusive development**

- To what extent the inclusive polices are really inclusive?
- To what extent inclusive cultures are there?
- To what extent inclusive practices could be seen?

Further explanation were given by the group to understand the term “Mainstreaming” in its real context-

“Disability is not a singular marker but is embedded in a matrix of poverty, class struggle and caste prejudice, types of impairment and above all patriarchy.”

“Inclusion is not about being on par with others, it is about having the opportunities to develop strengths and overcome weaknesses. Nobody can fit into another person’s clone.”

“...Real inclusion needs redefining disability as a development issue which should be based on individual needs and not disability certificates and poverty cut off points.”

4. REFLECTION FROM THE GROUP

To the question “WHY INCLUSION?” members came out with so many justifications. They also shared examples from their own experiences. We need Inclusion, because it is-

- A cost effective strategy as compared to other approach
- Socially desirable
- A win -win situation
- Requires least initial capital outlay
- A Poverty reduction strategy
- Promote active involvement and participation of members of community
- Extent of coverage is unlimited
- Enables acceptance of all
- A proactive approach
- Assured a society with

- ✓ Full participation
- ✓ Equal rights and
- ✓ Equal opportunities

where all should contribute irrespective of differences (disabilities)

- Empowering the individuals to contribute her/his mite
- Helpful in attaining MDG
- Fulfilling the needs of people with disabilities, that all should contribute with all non-disabled citizens,
- Helps people with disabilities to derive benefit from the decisions of decision makers
- To ensure greater life choices for disabled

As one e-forum contributor said: "The idea is that if we make it work for the most vulnerable, it will work for everyone. And that applies to traffic lights, shopping centres, movie theatres and airplanes."

5. THE DIFFERENT LEVELS OF MAINSTREAMING-

At the next stage, few more questions were put to the group for the further discussion, which were about the level of Mainstreaming

a. At a development level

Does mainstreaming disability at a development level put disability onto economic and social agendas (e.g. development of Poverty Reduction Strategy Papers and Sector-Wide Approaches)?

b. At a government level

How can different government departments be influenced to champion mainstreaming?

c. At an organisational level

How can mainstreaming be effective at an organisational level e.g. disability in the workplace

6. PROBLEMS FOR TRUE INCLUSION

While discussing the why inclusion, various important points also came in between, which were seen as the real problems in the way of True Inclusion. As it is seen that there are lots of policies and discussion at higher level but when it comes to the implementation very less is done. It is due to-

- NGOs largely focus on single disabilities
- Negligible involvement of PWDs / DPOs
- Lack of regular & sustained exchange of information between NGOs / Government / Private sector / Donor agencies
- No major link between disability to other rights based issues / movements

- Our own attitudinal barriers (where potential is limited by the vision (!) of the person governing the institution)
- Advocacy and lobby at the village level is almost non-existent in disability sector
- Lack of strong political support
- Policies are made unilaterally without much of convergence of ideas
- Negative portrayal of disability issues by the media
- Lack of capacity in government to effectively mainstream disability
- Lack of political will
- Negative customary beliefs and practices
- Poor implementation of laws and policies
- Non-domestication of international instruments by governments
- Majority thinks that the disability movement is about "of the disabled, for the disabled, by the disabled"!
- Not enough disabled people in positions of leadership

A comment from the group was: "We are now discussing on why there is so much talk at the policy level and not much translation is seen from policies to practices. I have noticed the most of the policies are not percolated from top level to lower levels who actually play a key role in the implementation. Why percolation is not taking place is one of the important questions we need to address. Perhaps the advocacy and lobby at the village level is almost non-existent in disability sector could be one of the reasons. Lack of strong political support is another reason. Policies are made unilaterally without much of convergence of ideas could be also a contributing factor."

7. CONCERN OF THE MEMBERS

Group has also shown some concerns, which need to be taken care of while talking of Inclusion in true sense. These are -

- Look at on How inclusion- Real and meaningful inclusion is possible only if difference in the ability is respected
- PWDs in key positions in different establishments (i.e. Govt, Orgn, funding agencies) as how many funders, governments and organisations have people with disabilities in their establishments? What position do they hold? Do their positions have any impact when it comes to policy formulation and implementation?
- Involve the 'mainstream development' organisations too
- Convergence of Government policies
- Human resource development
- Sometimes policies exclude people rather than to include them (i.e. Intellectual Disabled, Disability certificate, Income criterion)
- Sustainability (quality and accessibility to enjoy and participate)
- At the time of Disaster, this is one of the most vulnerable groups
- Awareness about Mental Illness

- Gender equity as sexual, physical and psychological abuse of people with disabilities especially women and girls (People with disabilities are seen as easy targets and 'victims')
- Governments and international organisations do not take disability issues more seriously as they do with women and youth issues
- The rural and urban divide, as one member wrote:
 “In rural areas expectations are lower and the pace of life is different so our kids find it easier to manage and be accepted. The low level of parental education becomes a boon in this respect. But on the other hand, we are relegating these kids to a situation without offering them choices. The child is performing the same chores and trades that his grandfather performed - he is well settled, his parents have no complaints. Many times I do not understand what is better- to be thrown out of a school because you are below the accepted standard or that standards of life are so low and poverty so overpowering that no choices are available?”

8. *From the field*

Group was very enthusiastic in sharing the examples from the real life. It enriched the discussion too. It was all about successful/ unsuccessful practices, prevailing myths, government policies, struggle for the cause and lots of. Lot of lessons can be drawn from the examples as they are narrated very lively-

- **Sudha Patel, Head Woman of a Village** (A classical example of inclusion at the grass root level). “Sudha Patel a blind lady, is elected as a headwoman (Sarpanch) of village Changa in Gujarat. Encouraged from her achievements, one commercial film with Gracy Singh (of Lagaan fame) in the role of Sudha is on the anvil.”
- **Urban myths and folklore** “In Zimbabwe where there is a myth that sleeping with a disabled person can cure someone of HIV virus. It is widely believed that people with disabilities especially; wheelchair users are not sexually active, as no one would want to sleep with them. They have therefore been regarded as 'safe-sex options' and so free from the HIV virus hence they are being raped.”
- **Inclusive Education in Bangladesh-** “About three years back, a national study on the situation of disabled children (within the primary school going age) found that among the approximately 1.6 million disabled children, only 4% had gained access to education. While for about 70% of the children out of schools, almost all could go to regular mainstream schools. But just because they were 'disabled children', they were barred from enrollment. So you see, in this area, Pakistan is not any different from other countries.”
- **PHC/CHC Doctors as a linkages at the grasroot** –“With the Help of Rehabilitation Council of India, Delhi - Blind People's Association, Ahmedabad conducted the short-term training programmes on Rehabilitation Management for more than 1800 PHC/CHC Doctors working at villages or blocks level. Before coming to the training, they had lots of apprehensions and after completion of the training they became the linkages between the organisations(BPA and other local NGOs) and the needy ones. Now, we have more referrals and more important is at right time, when interventions are most urgent for the person, who is in crisis. Rehabilitation institutes have very strong linkages and referrals in the field too. Where no other source of information is

available for PWDs, these medical professionals are very much helpful in getting timely help. I feel there is no better link than a medical professional in the remote area. We have lots of people coming every now and then for the support, who were/are referred by these Doctors from village PHCs.”

- **Level of awareness-** “While conducting a research on ‘IEDC Impact on the all stakeholders’ in Gujarat (India), I was in a meeting with all stakeholders including senior government officials. Across the group, very few people were aware about the benefits of the inclusion. Yes I do agree that Integrated Education for disabled children Scheme is run since 1974 in India. But fact is quite different. From senior govt. officials to local level, people still resist to the idea of inclusion.”
- **Change in the attitude can change the scene-** “It was 1998, prevailing situation was same in Gujarat state as in the other part of the country (India) or elsewhere in the South Asia. Less than 5% of CSN were going to the schools. Secretary of Education, Government of Gujarat was invited to Japan for presenting a paper on ‘Education of Disabled in Gujarat’. He prepared a paper with the inputs provided by Blind People’s Association (BPA), Ahmedabad and presented there in Japan. Fascinated by its overwhelming response, he again visited BPA and had a meeting with executive body. When it comes to his knowledge that only 1700 CSN are in the mainstreaming, he asked why don’t you have 10,000 children. To his surprise, he found that it is due to lack of funds. He told that fund will not remain be constraint. BPA called its networking partners (local NGOs) in the state and charted out the plan for expansion of the scheme. And In the next academic year (1999) the number of CSN in the mainstream was 17,284. Today, we are having more than 35,000 CSN in the regular schools throughout the state and it is still growing.”
- **Integration in real terms-** “I was on a field visit to a remote village in Western Gujarat. I saw children who were integrated even without an understanding of the theoretical aspects of inclusion. To my mind, their concepts were very clear - they wanted their village children to be educated. I felt very humble because they wanted me to tell them how these children with disabilities could be better served. I told them that Inclusion means accepting that these children have a right to education like any other child and accepting that all children are different. But that this is the essence creating an atmosphere where individuals with different appearances and abilities coexist happily. Sure it is not as rosy or simplistic but not as gloomy as we are in the habit of pointing out.
We have a child in a village in Surendranagar District, who has CHARGE and has multi sensory impairments. With five years of cohesive efforts she is now in the village school and happy.”
- **Delhi Metro: A Barrier Free Environment** –“It has also become widely accepted that better access for disabled people is better access for everyone. Delhi’s new Metro is a shining example of this. The access of stations and trains has been thoroughly addressed at the design stage and the whole system is a remarkable model of good access and good design for all passengers, those with heavy luggage, parents with small children, people with mobility, visual and hearing disabilities and elderly people. The same argument for making the built environment more accessible can apply to mainstreaming disability; better development for disabled people is better development for everyone. Inclusive education and

inclusive development not only enhance the quality of life of disabled people but also add quality to social development at large.”

- **Welfare or?** – “In Zimbabwe, there is the Disability Board, which is an arm of government, we have not witnessed any significant changes in the inclusion of people with disabilities in all matter concerning them. Imagine that a disability grant of Z\$10 000,00 (approximately US\$2.00) is given on monthly basis to those who are considered to be in most desperate situations. This grant is not even enough to cover for bus fare. Then one can conclude that there is a welfare policy for people with disability in Zimbabwe? Do you think I make sense? A government could go around the world boosting that we have the welfare of people with disabilities at heart. This is what is happening world-over.”

- **Long way to Inclusion** – “In Bangladesh for example, we have managed to get the issue included in the much debated national Poverty Reduction Strategy Paper (PRSP). However, while the PRSP has included disability issues to a great extent, as separate stand-alone sections in the poverty analysis part and again in the future strategic part, in many areas it is still looked at as a charity issue rather than a right-based issue. For example, in Bangladesh, we have two different ministries catering to education - the Ministry of Education and the Ministry of Primary & Mass education. Yet education of people with disabilities is under the purview of the Ministry of Social Welfare. The PRSP has no mention of shifting the issue to any of the mainstream education ministries. However, regarding accessibility, it does call for changes in the building code. We have maintained good but strictly working relationship with three successive governments in this country, and have got ourselves into all possible committees, taskforces, working groups etc. etc., and now like a Trojan horse, are trying to work our way through. We have achieved some great successes, some not-so-great successes and some failures so far. But with tireless energy, and enormous patience, we are sticking at our job, looking forward to some great days.”

9. THE SHOW IS STILL GOING ON...

Still the show is going on with -

- **“LEVELS OF MAINSTREAMING”**

- **“HOW TO MAINSTREAM”**

RESOURCES- new addition at the E-forum are-

- A press release and link to the CD-ROM, developed by Handicap International, the International Disability and Development Consortium (IDDC) and Source, titled "The Disability Convention - Making it Work". The CD-ROM will be launched at the 5th Ad Hoc meeting for the UN Convention of the Rights of Persons with Disabilities" in New York. This CD promotes the consideration of disabled people in international development through human rights.
The CD is available on request or online (www.iddc.org.uk/cdrom) .
[Press release 1 Launch of the CD Rom on Disability Rights 31-01-2005.doc](#)

By- AlisonSizer, Programmes Officer – Asia, Healthlink Worldwide

- A book on disability issue is published by Haranand under the series Shakti Books with a title '(Dis)Embodied Form: Issues of disabled women' written by Anita Ghai
- A paper on inclusion by Gladys Charowa
- A paper on the inclusion of children with visual impairments by Nandini Rawal