



DISABILITY KNOWLEDGE AND RESEARCH PROGRAMME

ROUNDTABLE 2:

MAINSTREAMING DIASABILITY IN DEVELOPMENT

(Final Report of the E-FORUM discussion as on March 30,05)

Sponsored by

The Department for International Development (DFID), UK

&

Organized by

Blind People's Association (BPA), India

in association with

Healthlink Worldwide (UK)

Guidance

Dr. Bhushan Punani

Executive Director,
Blind People's Association (India)

Niki Maniam

Web Communication 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

CONTENTS

Acknowledgements

Introduction

What are the E-forums & roundtables?

- What are the roundtables?
- Aims and objectives of the roundtables
- E-forum discussion: exchanging views through e-medium

Discussions before the Round Table-II

- Why mainstreaming?
- Defining mainstreaming
- Reflection from the group
- The different levels of mainstreaming
- Problems for true inclusion
- Concern of the members
- From the field

From the Round Table-II

- Presentation summaries
- Open group sessions
 1. Mental health and mental illness
 2. Mainstreaming girls and women with disabilities, and disability and sexuality
 3. Roles of DPOs
- Roundtable outputs
 1. Recommendations for roundtable 3
 2. Mainstreaming indicators
 3. How to include disability in the Millennium Development Goals
 4. How to engage with mainstream development organisations

The Show Must go on... (Discussions after the Round Table-II)

- Stages of Inclusion
- How to Mainstream
- Reflection from the Group
- The Last Phase: Case Studies

Conclusion

Annexure

Resources

Acknowledgements

I would like to express my deep gratitude to Healthlink Worldwide, UK for providing this wonderful learning opportunity. Many thanks to Niki for always being a great help and guiding me whenever & wherever I needed. I would also like to express my deep gratitude to Dr Bhushan Punani for constant guidance and encouragement. He is a great source of inspiration not only for me but also for many. And last but not least, I am thankful to you all, the members of the E-forum, who made this discussion a real success.

Pramod Kumar Gupta
Moderator, E-forum-II

Introduction

DisabilityKar is a great platform for networking, learning, sharing and working together towards the goals we all feel strongly about. The idea and operation of E-forum is very critical to the success of the Round Tables. It is true about the RT-II also. E-forum-II discussion was started with the theme “Mainstreaming Disability in Development” from February 1, 05. Members discussed about the various sub-themes i.e. Why Inclusion, Levels of Mainstreaming and How Mainstreaming with the live examples from the field during the period.

What are the E-forum & roundtables?

□ **WHAT ARE THE ROUNDTABLES?**

The roundtables are a series of three discussion forums organised as a part of the Disability KaR programme, a Department for International Development (DFID) programme that aims to share learning and research about the relationship between disability and poverty, and mainstreaming disability in development. The roundtables are organised by Healthlink Worldwide and a national disabled people’s organisation (DPO) in each of the countries where the roundtables are taking place.

The roundtables are facilitated discussions aimed at creating space for people to share their experiences and perspectives. They are not training events aimed at teaching people skills or passing on information, and therefore they do not have a fixed agenda but develop according to people’s expressed needs and the priorities of participants as a group.

□ **AIMS AND OBJECTIVES OF THE ROUNDTABLES**

The goal of each of the roundtables is to provide an opportunity for decision makers to hear and learn from the views and experiences of people with disabilities, DPOs and organisations and institutions working on disability in the South. The aim is to help bridge the communication gap between stakeholders at the grassroots and policy makers. They are held to provide an opportunity for policy makers to learn grassroots practitioners.

The roundtables are practically focused and designed to articulate practical steps for moving forward on linking disability policy and practice in relation to:

1. Mainstreaming disability in development &
2. Links between poverty and disability

Some of the objectives of the roundtables are:

- Provide an opportunity for decision-makers to engage in discussions with people with disabilities and DPOs
- Provide a space for participants, in particular people with disabilities and DPOs to share learning and reflect on current practice
- Engage stakeholders in discussion and dialogue around issues affecting the use of knowledge to change policy and practice
- Bridge the communication gap between stakeholders at the grass roots and policy makers
- Generate debate and enable the sharing of experiences and learning about the links between poverty and disability, and mainstreaming disability in development
- Provide a number of case studies of the experience of organisations in mainstreaming disability in development

Each of the roundtables provides a forum for discussion around a specific theme:

- ❖ Disability, Poverty and the Millennium Development Goals (roundtable 1);
- ❖ Mainstreaming disability in development (roundtable 2) and
- ❖ Mainstreaming in practice: a case of Inclusive Education (roundtable 3)

They provide an arena for around 50 participants from DPOs, non-governmental organisations (NGOs), bi-lateral agencies, UN agencies and national governments to discuss issues related to the theme, share ideas, experience and good practice, reflect on current practice, and learn from one another. It is hoped that they will provide a catalyst for mainstreaming disability in development. The roundtables are not training events with specific learning activities; rather they are open, frank discussions, where learning takes place through the sharing of experience and ideas.

□ ***E-FORUM DISCUSSION: EXCHANGING VIEWS THROUGH E-MEDIUM***

The roundtable discussions do not only take place over the three days of each of the forums. They begin four weeks prior to the actual Round Tables and continue for four weeks after finishing the RTs on the topic decided for the particular RT on the roundtables' electronic discussion group at –

www.dgroups.org/groups/disabilityKaR/

E-forum, a flow, which is passing through three RT's with various interlinked topics. The main aim of E-forum discussion is to invite as many people as possible to share their experiences and learn from others electronically. Due to so many limitations, it is not possible for everybody to physically attend the RT. E-forum provide an opportunity for them to get involved with the main RT discussion. 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 was to explore how to mainstream disability in development, providing an arena for reflection on, sharing of and learning from experience. This roundtable focused on planning for Mainstreaming Disability in Development (a “how to” discussion).

Discussions before the Round Table-II

The discussion was started four weeks before the actual Round Table. Members discussed the various points pertaining to the main theme, as it was a guided discussion.

1. 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.

2. 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. It helped everybody to get an insight. Some of the definitions of Inclusion/ 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 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"

"...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."

3. REFLECTION FROM THE GROUP

To the question “WHY INCLUSION?” members came out with so many justifications like; 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 and many more.

4. 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 levels of Mainstreaming-

- a. At a development level
- b. At a government level
- c. At an organisational level

5. PROBLEMS FOR TRUE INCLUSION

Members also identified 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. Members also quoted some more reasons as the barriers to the true inclusion.

6. CONCERNS OF THE MEMBERS

Group also showed some concerns, which need to be taken care of while talking of Inclusion in true sense. These all were related to the Inclusion in true sense. For example- Involvement of the 'mainstream development' organizations, Convergence of Government policies, Awareness about Mental Illness, Gender equity, The rural-urban divide, etc.

7. FROM THE FIELD

Group was very enthusiastic in sharing the examples from the real life. 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).
- Urban myths and folklore “In Zimbabwe where there is a myth that sleeping with a disabled person can cure someone of HIV virus, which sometimes leads to the rape of disabled person.
- PHC/CHC Doctors as a linkages at the grasroot –“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. for PWDs, these medical professionals are very much helpful in getting timely help.

- Level of awareness- about IEDC scheme among all the stakeholders in Gujarat (India).
- Change in the attitude can change the scenario- How the Education secretary could be helpful for expansion of the Inclusive Education project after the proper knowledge.
- 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 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.
- 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.
- Welfare or? – “In Zimbabwe, 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?

(Note- this is the summary of the E-forum-II mid term report. For full text refer to the midterm report listed in resource section of the group)

From the Round Table-II

This roundtable, held in Ahmedabad, India, was the second of three regional roundtables being held as part of the Disability Knowledge and Research programme (Disability KaR). It had the theme “Mainstreaming disability in development”, and was attended by 49 participants. Among the participants were the Chief Commissioner for Persons with Disabilities of the Indian government, representatives of mainstream international / national non-governmental organisations (INGOs), and representatives of regional, national and grass roots disabled people’s organisations (DPOs).

The discussions focused on the:

- Concepts of mainstreaming and inclusion
- Challenges of mainstreaming disability
- Strategies to overcome the challenges identified

A number of sessions at the roundtable gave participants the opportunity to make presentations about their work, some of which were examples of how the challenges to mainstreaming and inclusion had been overcome in practice, including presentations on:

- Community Approaches to Handicap in Development programme
- Mainstreaming disability in community development in South Asia
- Orissa State Disability Network
- Project Anjali
- The Disability KaR programme, the first roundtable and the electronic forum discussions
- Summary of the discussions at the Voluntary Service Oversea (VSO) India roundtable
- World Bank India Disability Study
- Department for International Development, India
- The three-legged stool of disability

On discussing the **concepts of mainstreaming and inclusion** it was clear that there was a great deal of debate amongst participants as to whether mainstreaming was an outcome of the strategy of inclusion, or vice versa. No agreement was reached and the debate continued. Participants developed a list of indicators that could be used to monitor mainstreaming or inclusion (see full report of the roundtable-II).

The participants identified the following as being key **challenges to mainstreaming disability**:

- Information and awareness
- Access and accessibility

- Education and employment
- Role of stakeholders, actors and DPOs
- Attitudes and culture
- Policy and legislation

The participants identified the following as being **strategies to overcome these challenges**:

- Mandatory development and implementation of disability related legislation
- Sensitisation and awareness raising activities (both focused and mass media) related to both disability issues and disability related policies and legislation
- Development of information, advocacy and awareness raising materials in accessible formats and languages
- Capacity building for DPOs and people with disabilities in advocacy, policy and legislation
- Capacity building for government worker in implementing disability legislation
- Sensitisation and capacity building for stakeholders affecting accessibility for people with disabilities in carrying out accessibility audits and the creation of an accessible, barrier free environment
- Data collection to demonstrate the prevalence of disability and enhance understanding of disability issues
- Inclusion of disability issues, using positive images, in teaching and learning materials and curricula at all levels of education
- Inclusion of issues related to the education of people with disabilities in the teacher training curriculum and materials
- Development and implementation of skills training programmes for people with disabilities relevant to the employment market
- Networking from international to local level to ensure that information, experiences and good practice is shared between the state, DPOs and service providers

Open group sessions allowed participants to discuss issues raised during the roundtables, for example the Millennium Development Goals, defining mainstreaming and inclusion, mental health, the roles of DPOs, and mainstreaming girls and women with disabilities, and disability and sexuality.

The roundtable resulted in participants working together on four outputs:

- Recommendations for roundtable 3
- Mainstreaming indicators
- How to include disability in the Millennium Development Goals (MDGs)
- How to engage with mainstream development agencies

(This is a summary of RT-II discussion; refer to the report for full text)

The Show Must Go On...

In the second half after the RT-II, the discussion on E-forum was mainly focused upon two topics namely “**STAGES OF INCLUSION**” and “**HOW TO MAINSTREAM**”. To make the discussion more fruitful, some points/ questions were raised by the moderator about the above mentioned topics.

Stages of Inclusion

After justification for the Inclusion, we need to be clear about where to look for Inclusion. It is indeed a matter of concern how can we influence the government and its various departments to mainstream disability in development in particular and society in general. We need to know the stages of Inclusion, so that we can clearly devise the strategies for implementation, means the different levels of mainstreaming-

- 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)?

- At a government level

How can different government departments be influenced to champion mainstreaming?

- At an organisational level

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

How to Mainstream

This was the last part of the discussion. In the starting, a point was raised that we should talk about ‘How’ part rather than ‘Why’. And it is very important to talk about the processes (How part) as well, without which any idea is of no use. Few points were raised for guided discussion, which are-

- How can Civil Society Organisations and Disabled People’s Organisations help governments to turn legislation and policy into reality? (Lessons in partnership)
- What lessons can be learned from other sectors e.g. mainstreaming gender that can be applied to disability? (Convergence of ideas)
- How can civil society organisations, governments and donors encourage organisations to mainstream?

Moderator also encouraged the group to quote the examples from their own experiences.

Reflection from the Group

The Educational system needs to be overhauled- so that it can accommodate all children irrespective of any difference or disability. As one member said - "...The fact is that our education system is not really working for the vast majority of the children already in it and until we address that, all talk of inclusion is somewhat meaningless. I agree that visibility is important, but only a very small first step."

Inclusion of the intellectually disabled – as one member put it in this way "...I still continue to ask the same question about the involvement and inclusion of the intellectually disabled in the process of reaching the goal of One school for All..."

"Children with mental handicaps are consistently ignored in our efforts toward inclusion. Without looking at how classrooms are structured and learning takes place, we cannot expect this to change. Activity based learning is essential for all children; for children with mental handicaps, that goes double. It's also so much more fun!"

One member quoted an *example*- "...Here in Dehradun, we started a help desk at the local government hospital to assist people with disabilities in obtaining their Disability Certificates from the CMO. What we found was that our presence at the hospital made life easier for everyone: people were so happy to find someone who would smile and answer their questions that they started coming to us for all sorts of things which had nothing to do with disability. 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..."

Link of disability with other issues- Thus enabling a more inclusive environment where everyone's needs irrespective of their sex, age, caste/class/indigenous group, impairment etc. will be catered to. As George Abraham from AICB in a recently held show on "Big Fight" on NDTV said "...why are disabled people only invited to shows which discuss about disability issues only. They are equally interested in politics, sports, music etc. and want opportunities to share their viewpoints like anyone else..."

Concern about the situation of disabled women in Asian countries and their involvement in the development process – Some hard facts about status of women with disabilities shared by one member are given below

'Women with disabilities are estimated to represent from 15-20% of the world's female population, the majority living in developing and transitional countries, their participation from leadership and participation in the national and

international development community is a serious impediment to efforts for the gender equity, development and human rights.'

'However persons with disabilities offer an untapped resource for international development - in particular women with disabilities are under-represented and under-served in every aspect of the development field as partners, staff and beneficiaries of development programs. When I visited international organisations like CARE, UNICEF and few others working on World Bank projects, it was disappointing to see none of their projects had PWD's working and more so, they accepted that they had not even thought of it.'

The right to information & the right to expression - "...this must be addressed in the process of mainstreaming disability. This means that every support must be given to the voice of disabled people...both disabled people and non-disabled people combining with shared objectives, shared effort and also power-sharing."

Inclusive Schools – "...We can see that in education where child-centred education is given for disabled children and this unquestionably is a better education for all children in all schools. For example, in a primary school health programme (called SeHAT in Delhi and Mumbai) a child-centred and activity-based approach to learning was introduced to health education classes. Teachers and other education staff were trained. The impact on the knowledge, skills and personal development of the children was marked: the children spoke well about the facts of nutrition, hygiene and the environment, displayed good skills e.g. weighing, measuring, recording facts. They were able to answer real life questions that showed confidence in their understanding and thorough knowledge which rote learning does not give. On top of this, the teachers found that this teaching approach enhanced other subject learning e.g. history and geography."

One member from Bangladesh quoted one example of how they increased the enrollment ratio in the schools. He said, "...experimentally we announced extra stipend for the disabled children who would come to school for three rural primary schools. The enrolment increased, I saw the results within a month. We saw that girls' enrolment has risen tremendously in Bangladesh for the stipend and free education offer from the government... We need to do something extra for these people to overcome the physical barriers to create the demand in infrastructural changes..."

Economic improvement – it is only possible through (as one member said) "...empowerment; village women's self-help groups in India show this clearly. Both lead to greater community participation and better governance starting at the Panchayat level."

Assistive Technology Unit- One member was having a greater concern for creating an Assistive Technology Unit, which can be an Assistive Technology service provider to individuals with disabilities.

Gender equity – is one of the major concerns, which should be given prime focus in the present world situation.

Seeing in the Dark (SitD)– Development communication says about three D's- Do, Document and Disseminate. There was an installation at BPA during the RT-II. It was an experiential learning tool, which gave an idea about the blindness for the sighted visitors. Some of the participants visited the SitD and found it very useful as a tool for advocacy and awareness. As one of the members mentioned the fact, "...many parents of vision-impaired students wanted to go to Black Out to better understand the disability. I think it's a great way to lighten people up and try something different."

Another member pointed out very rightly, "...It is hoped that SITD has an impact upon its' visitors that produces changes in both attitude & action, that advocate inclusion. These changes will be specific to each different visitor, according to both their experience of different disabilities and their daily activity in the wider world. Amongst these visitors are those involved in policy making and recognised as having powerful positions, who can help to promote changes at 'high' level. Their potential contribution is highly valued. However, the largest group of visitors to SITD is made up of friends and family.

The event was so successful that those who wanted to visit the place had to take prior appointment. One member quoted, "...When the installation was opened for public viewing little did we expected that there would be so much of overwhelming response from people. Other day when I visited BPA to see how things were going, I was surprised to hear from Pramod that now people have to take an appointment to visit this exhibition, because for the week, the booking was done. I was really surprised to hear that response..."

Few of the members further stated that we should also consider the other disabilities as part of such exhibitions. As one member made it clear by saying, "...what I feel that it is one token example specifying to the visual impairments to realise about the problem and to understand how all we are those who are involve in the development process are in a complete dark environment about the problem of the people those who are with us in different form of impairments."

Another member quoted, "...my staff were awestruck and suggested that if multiple disabilities and other such disabilities that can be included in such an activity, it may be the best way to sensitize professionals and parents about disability related issues."

One member answered to the above reservation and provided information as said, "...Sense Scotland has a similar project for creating awareness about

deafblindness and for sensitization of professionals and family members, in which they have used various textures, hanging objects and smell. All this is in complete darkness and silence...”

Dark Restaurant-One member also searched the web for such an experiments and found very interesting things. She provided a web link about the *‘Dark Restaurant’* to the group. Another member went further in his search and he got a whole lot of information searching through Google. He shared, “...the concept sprang from dinner parties held in the home of a blind man who opened a restaurant in Zurich in 1999 staffed by blind people. The "Dining in the Dark" theme moved to Germany, Paris and New York, and has now arrived in the southern hemisphere courtesy of theatre producer Paul Farrah...”

Disability: Human right V/s Development issue- it was very interesting to see the debate over ‘disability as a human right issue or a development issue’. One member was puzzled as he said “...I am wondering what are the basic difference or indicator to label this either in right or development issue.”

Another member very clearly pointed out the basic differences between both – the development V/s right based. He very rightly said, “...You raised the question about disability being a development or a rights issue. I think it's both, not one or the other. This is because development is now recognised to be a rights issue. Rights can most easily be related to a legal framework. So if there is a law or Act in a country e.g. as in India and Bangladesh about what the Government says it will do for disabled people, then those things are the rights of disabled people. Also, in India the Constitution says that all citizens will be equal, so that too is a relevant right for disabled people. The new UN Convention for Disabled People, of course, will be the sharpest instrument to apply when it is finally completed and signed.”

She further stated, “...The Millennium Development Goals are certainly relevant to provide leverage when lobbying for inclusive development. The President of the World Bank made a statement on the International Day of Disabled Persons 2002 that is quoted on the DisabilityKaR website. He said unless the needs of poor disabled people are addressed, the poverty reduction Goal would never be achieved. The World Bank Disability Advisor, Judith Heumann, continues to use the MDGs in relation to disabled people. The International Disability and Development Consortium is also applying the MDGs to disability and development as a lobbying tool...”

One other member clarify it further as ‘...I feel there is a difference in looking into disability from contexts of either development or human rights. Development context deals rather macro aspects, while rights say more about micro or individual aspects. Also disability as a development issue cut across all sectors like other issues it has linkages with, and as rights issue gives basis for fights for achieving rights by individuals from a sector.”

However one member pointed out that sometimes we consider disability as a right based issue and other time as a developmental issue. But we never consider that we are also human beings and should be given equal weightage in all spheres of life. He very strongly recommended, "...now we have to think why this development planner and policy makers and builders are forgetting about the existing of us those who we are suffering as we are the citizen of this world by birth we have the right to enjoy all this but yet why it is missing out..."

He further quoted Dr. Ammartay Sen, "... he has given the poverty reduction strategy plan and mentioned there that how it is possible to make it success without involving them." He also put in to the notice that, "...why always after any initiative we should shout, why there is no mechanism yet being developed..."

The last phase: Case Studies-

E-forum-II was stated with a theme "Mainstreaming Disability in Development". We had started our discussion with 'Why Inclusion?' and group justified the idea of mainstreaming with an overwhelming response. We further proceed and came to the 'levels of mainstreaming' and then 'Process of Mainstreaming' or 'How?' part. In the last part of the discussion members were requested to share the case studies as live examples from the field. These case studies could serve the field in a bigger way as we could learn from the successes and failures of others. These case studies with the following details could be used for developing the future models of Inclusion. The details were-

- * Location of such practices
- * Extent of participation of Government
- * Extent of legislative support
- * Support of community
- * Extent of participation of the stakeholders
- * Extent of acceptance by the developmental system
- * Extent of sustainability of the approach
- * Nature of convergence various Government programmes and developmental system

In response to the above statement, one member said, "... when we are taking about mainstreaming then do you feel that it is too necessary for location of such practice? Is it not enough that we are living in our house where we are one person is disabled but they are cooping us with our impairments and trying to do maximum thing considering our impairments except what is not possible for them economically from there they are being stooped and for that definitely we can not blame our family. So family is the best location of such example..."

Another member said, "Family based approach would be more effective and sustainable for the future." He further reiterated, "... Activities like SITD have a vital role to play in sensitizing the families of disabled people into deeper understanding. This is not only an understanding of their problems (individuals and families) but also their abilities."

Conclusion

It was amazing to see people with wonderful thoughts and innovative experiments in the process of Inclusion. More and more people from different walks of life joined the group and it became much more inclusive in meantime. It's like a Urdu verse - 'ME AKELA HI CHALA THA JANIBEN MANJIL, LOG MILTE GAYE AUR KARVAN BADHTA GAYA' (I was all alone on my way towards my goal, people met along the way and formed a big group with same goal).

We as a group having one direction, and that was 'Mainstreaming Disability in Development'. We started discussion with "Why Mainstreaming". In the process, we identified so much of 'WHY' and 'WHYNOT'. In the meantime, group put light on various problems to the true Inclusion. Then members went further and defined the different levels of mainstreaming. The theme further developed in "How to Mainstream" and members contributed various examples from the field, which enriched the discussion and the understanding.

It was a humbling experience, where people could contribute at their own convenience and be enriched with other members' knowledge and experience. It seems that world has no boundaries and we all are free to express our thoughts. If we have such platform for sharing and learning, it would be very easy to overcome our problems and learn new lessons collectively. Again, it is quite inexpensive medium, which is very much affordable.

We need to encourage such initiatives and give them permanent stature, so that people from any part of the world can make use of them for sharing their own experience & to solve their own problems. Members were/are very much interested in continuing of the E-forum forever. One member very interestingly pointed out, "...whether the E-Forum could be prolonged beyond its planned duration. As far as I understand, the E-Forum is now supposed to work for only about six months...Based on this experience, and seeing the amount of interest this has generated, I asked the people behind this Forum, could this be prolonged?" Hope someone is listening!

RESOURCES

New addition at the E-forum were-

- 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- Alison Sizer, 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

URL Links

- ❖ link for **Dark restaurant** on the address bar.

<http://www.time.com/time/europe/magazine/article/0,13005,901020729-322741,00.html>

- ❖ The exact URLs on Dhaka show in local media and Healthlink site.

<http://www.healthlink.org.uk/world/seasia-news02.html>
<http://www.thedailystar.net/2003/12/15/d31215060160.htm>
<http://www.thedailystar.net/2003/12/24/d312241401100.htm>
<http://www.newagebd.com/dec3rd03/211203/nat.html>

ANNEXURE-1

EQUITY TO WOMEN WITH DISABILITIES IN INDIA

Gender Justice to Differently Abled Women

VOICE of Challenged Women

Stake holders spoke from their Heart-

Hemavathi CBR worker from Narendra Foundation, “Talents are never sought or exploited from differently abled women. Discrimination on gender based intensifies when the girl has a disability. Tell us, who encourages women with disabilities? - Society? Family? Government? Women with disabilities are often singled out in a crowd, ridiculed in public. This hurts us most. Lack of facilities, something as basic as a toilet is a luxury for us. When girls in general have difficulty in getting married, imagine our plight.”

Husein Banu, Teaches Braille in Samuha, Koppala – “We faced a lot of difficulties when undergoing education with so called normal students. The major problem I have faced is constant discouragement from the teacher, who did not allow me to participate in the school activities such as games, drama, because I am disabled. That hurts me a lot. Government schemes are just on paper and does not reach poor people. Employment for blind persons is so scarce, I do not understand who is getting benefit from the reservation?”

Prof Suvarna, Head of the psychology department- “To sum up, the plight of a woman with disability, to avail any benefit from different schemes is nothing but "stress, challenge and struggle"

Nita Patel, Navjeevan Mitra Mandal, Bhuj, Gujarat- “Society projects women with disabilities as dependent, helpless individual. We need love, not mercy. It is not lack of ability but lack of facilities that make us dependent and we remain uneducated. Out of 35,000 people with disabilities in Kutch, nearly 18,000 are women and only 2000 persons have means of livelihood. We are deprived of childhood, play, education and finally right to family. I wonder why can't I become a mother! DO not I have aright to family, to motherhood!”

Dr Sangeetha :”All that we need is to boost our confidence and public support. We do not want special rules but relax existing rules. Public servants should have dedication and sensitivity to meet our basic requirements.”

Suchitra, Narendra Foundation: ”Disability is not a curse although it is cited by the society as such. What really affects us is discouragement and discrimination.”

Asha B, CBR Network: “I do not want to depend on others. I want to achieve self reliance in life .In Past, I found it very difficult to find employment, but now that I

am working in CBR am happy. Government says that they have reserved jobs for Disabled but I do not see any job advertisement in Paper to recruit Disabled persons! When I go to private companies they show sympathy but do not give me a job!"

ANNEXURE-2

RECOMMENDATIONS (PART- I) ACTION BY THE GOVERNMENT OF INDIA

Charter of Rights of Women with Disability: There is an urgency to spell out a special charter for protecting rights of persons with disability with special provision for protection of rights of women with Disability

Separate Directorate for all States in India: All State Governments must create a separate department or directorate for persons with disability. Sufficient funds and infra structure to be provided to these departments.

Creation of a National Academy for persons with Disabilities: with several sections such as education, rehabilitation, medical treatment etc. This academy can acts as an umbrella for all the multidimensional needs of persons with disability.

Gender Justice for Women with Disability: Environment has to be created in a such way that Women with disabilities feel free from “Fears of Safety or personal attack on them because of their vulnerability, obviously women face “Double Risk”

Forced mass hysterectomy for severely mentally challenged girls: Participants condemned such cruelty, although intention may appear good. Rather than such a barbaric action, protective measures should be taken so that violence on such vulnerable girls/ women does not take place.

Sexual exploitation of Women with disability girls and women: Safety of these girls is always in jeopardy, as they become doubly vulnerable. All efforts should be made to curb such acts, culprits should be taken to task, and Speedy actions at police stations and at the courts should be taken to punish the culprits

Formation of District level CBR societies: Introduction of CBR societies in every district where stake holders and the community should be involved to identify all Women with disability, identify their issues and plan for mitigating their sufferings

Formation of village level self help groups of women with Disabilities: SHGs to be set up for women with Disabilities and inclusion of women with disabilities into existing micro credit activities, locally relevant vocational training and self and group employment opportunities to be created

Development of Information Booklet: There is an urgent need to develop a booklet which gives basic steps involved in seeking assistance from various government schemes or private assistance, concessions, scholarships available

for Women with disability. This booklet should be printed made available to all the districts, NGOs and others. The booklet should give designations and phone numbers for each officer to be contacted

Information pamphlets through dept of information and publicity :In a summarized version, Information pamphlets for all beneficiaries should be printed and made available in large quantities for direct dissemination to beneficiaries through DPRO and Field publicity Offices

Reservations in schools and colleges: If women with disabilities are seeking admission, priority should be given by schools and colleges.

Easy Access: In spite of continuous demand for the last two decades, this has not happened. All important government buildings, government hospitals, government hostels, Vidhana Saudha, Mantralayas, public places, railway stations, bus depots, should have easy access to Women with disability persons

Insurance for Women with disability: Health insurance and Life Insurance facilities have to be extended to Women with disability.

Issuing of disability certificates: Procedure of getting certificate from local authority is cumbersome. There is a need to simplify the procedure and make it uniformly available from one single authority. Once such a certificate issued it should be valid for lifetime. Women with disability should not be made to run around from one desk to another

Ban On Begging by Women with disability: Zero tolerance to begging by Women with disability should be introduced, particularly in major towns, railway platforms, inside the trains. A quick analysis should be undertaken as to who are these persons who generally get involved in begging and this practice should be curbed. Adequate Social security measures for this bottom most vulnerable section of society must be a priority for each district.

Tele Rehabilitation units should be established at least in all the block level hospitals for referral support.

Prevention of disability through genetic counseling: There is legal ban in Karnataka on marriages within family, however this practice is rampant in rural South India. Ill effects of such practice should be widely disseminated through small pamphlets, posters, rally at PHC level.

Construction of Toilets: Toilets specially designed with enough room for taking the wheel chair inside and with western type of seats should be constructed in all public places, i.e. railway station, bus depots, market places, cinema houses, shopping centers, libraries, colleges, schools government hospitals, nursing homes

Subsidies for Individual toilets: For families with Women with disability persons, 50 % subsidy should be given for a low cost toilets facility for rural and urban poor. District collector should be asked to furnish list of families with Women with disability persons and on a priority basis, low cost housing and toilet facilities should be given.

Appointment of a councilor: A trained councilor should be attached to every district hospital to carry out education, counseling of parents of a child with disability as well as counseling of women/young girls with disabilities, and awareness activities. People with CBR orientation should be appointed

Compulsory enrolment of girls with Disability in ICDS: and elementary school should be implemented with necessary capacity building of Angawadi workers and teachers.

Special Employment exchange to be created in every district: In every District Special employment exchange cell to be located for those Women with disability wanting to get employment in government or private work sector

Special efforts for marketing: Government should set up a show room in every district for sale of products manufactured by WOMENWITH DISABILITY. This show room in a major market place should be available free of cost at free of cost in the city. Also telemarketing (orders on phone) from that place should be promoted. This can give employment to the persons with disabilities.

Reservation for employment and education institutions: Rehabilitation and affordable adaptive technology must be available for women with disabilities and women with disabilities must be involved in the development and production of these devices.

Government to Assist NGOs: Organizations dealing with Women with disability, Leadership training projects and independent living services, research institutions, and universities must collect data on women with disabilities, their needs, education facilities available etc.

Government supported small scale industries may be urged to set up technically qualified manufacturing units of low cost affordable sanitary towels and also there is a need to introduce practice of using adult diapers

ANNEXURE-3

Seeing in the Dark

(An exhibition that gave people the opportunity to experience the world from a different perspective By Derek Thorne, SARPV)

Seeing in the Dark was an exhibition that ran from 15th to 21st December at a gallery in Dhaka, Bangladesh. The aim was to allow visitors to experience Dhaka from a different perspective, that of persons with disabilities. But the organisers, Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV, Bangladesh) and Healthlink Worldwide (UK) wanted to do something deeper than a photography or art installation - they wanted to simulate the lives of people with disabilities as realistically as possible. So for 6 days, the gallery venue was plunged into absolute darkness, to simulate blindness, and it was filled with scenery, sounds and scenarios to recreate Dhaka life. For the visitors, it was a completely new experience.

During this time it was my privilege, as a volunteer currently working with SARPV, to be involved with this project. The idea originally came out of a meeting between SARPV and Healthlink Worldwide in May 2003, but the exhibition really came together in a rushed and exhilarating period in December 2003. We began by realising that this project could have more functions than simply producing a good end product. We wanted the exhibition content to be designed by people with disabilities - in particular, by people with visual impairments, because for this exhibition, the focus was blindness. And in doing all this, we could involve the people with disabilities in a number of stages of the exhibition preparation, including designing the content, and recording the sounds to be played inside the space. Furthermore, the exhibition was fully run and staffed by people with disabilities, with roles including a guide, actors, sound operator and receptionists.

We began working with our group of people with disabilities four days before the exhibition began. It was a group of about 25 people with visual impairments, combined with about 5 people with other physical disabilities - we referred to the group as the participants. We paid them all for their time, as they were often spending whole days working with us. We discussed the working conditions and pay, etc. when we first met up with them.

In retrospect, we would have benefited from having more time to collaborate with them; in the event, many of our ideas of involvement could not be fully explored. Still, we began with a discussion on what should be in the dark space: what kind of things did the people with disabilities feel were important in their lives, and what did they want people without disabilities to experience in a new way?

The results of this discussion were most interesting. We heard about how roads are difficult to cross, how hard it can be to put on the right piece of clothing, and

how impossible it can be to distinguish between Taka notes by touch alone. (IN BANGLADESH REPEATED RESIZING OF PAPER-CURRENCY RENDERED SAME SIZE OF TAKA NOTES BUT OF DIFFERENT DENOMINATIONS WITH ONLY COLOUR DIFFERENCES)

Following this, the participants set about gathering material for inclusion in the exhibition. In the case of objects and scenery, SARPV staffs were on hand to buy the necessary items. But we also wanted to include sounds in the exhibition, and so the participants were trained to use simple sound recording equipment, and they went around Dhaka to record important and interesting sounds and noises.

By this time, other SARPV staff members, together with local carpenters, were beginning to build the exhibition space. SARPV was joined by Simon Allen, a British artist, who has experience with exhibitions and soundscapes, and also David Curtis, Healthlink Worldwide's (the then) regional link coordinator for South and South East Asia. (CURRENTLY HE IS HEAD OF PROGRAMMES, ASIA) The first task was to black out the gallery space - to remove even the tiniest sources of light, which would allow visitors' eyes to adjust and see some of the objects around them. We did this with a liberal combination of paper, black paint and thick, black tape. We also needed to divide the gallery into the dark area (which was most of the gallery space, and consisted of a number of rooms without doors between them), and a smaller, lit reception area. The carpenters were excellent in constructing a wooden barrier, with entrance and exit, to divide the two. We finally fixed three layers of black curtain to the entrance and exit to allow visitors to enter without letting any light in.

We then had to fill the space with our chosen scenery. We divided the space into seven zones: a rickshaw, a road area, a garden, a lottery (where visitors could not see the numbers on their tickets), a wardrobe with some clothes to choose from: a Braille section (in which people tried to match to pieces of identical Braille from a mixture of them) and finally a shop. The scenery was usually simple - a few pot plants in the 'garden', plus leaves hanging from the ceiling, for example. We also got an actual rickshaw into the gallery, and lots of sand and stones for the road area.

Along the way, we had one long, thick piece of rope to trace the route, and visitors were given canes to make their way along it. One of the participants worked as the guide, to help visitors around, and there were three actors along the way - a rickshaw driver, someone selling lottery tickets, and a shopkeeper. We gave the visitors fake money as they went in, as well - pieces of paper the same size as Taka notes. With this money they would pay for the rickshaw, lottery tickets, and so on, without ever knowing what change they were getting.

The final element was the sound - we had two sets of stereo speakers, which were linked up to one central sound control desk within the dark space. One set created the road sound, as well as some garden atmosphere. The other played out a story, which visitors listened to while sat in the garden area - it described a

real-life case of a young girl with a disability who was sexually abused by her uncle.

It was certainly a lot of hard work to set up the installation, but it was a delight to be involved once it was all running. Regrettably, we did not leave any time between completing the building stage and beginning to admit visitors. We really needed a few hours for the participants to get used to their roles as guides, actors or whatever - and in fact, we had plans that they should show each other round in groups, and assess each other as they did so. But, as was often the case, time was not on our side.

So in reality, the experience became better and better as the days of the exhibition went by. Certainly, by the third day, the exhibition was being run completely by the participants, but until then technical assistants (like me, I suppose) had to be involved as well.

Responses to the 15-minute tour in total darkness were, in general, very positive. Because the publicity was produced at fairly short notice, the number of visitors was limited to about 150. However, we were quite happy with the variety of participants - members of the public, plus students, schoolchildren, NGO workers from Bangladesh and abroad, journalists, researchers and an architect. There was a feeling that the visitors were somewhat "middle class", and this would have a lot to do with the location of the gallery, in the affluent suburb of Banani, Dhaka. However the venue was practically ideal in itself, so we can have few complaints.

One recurring theme to the comments was that this was an experience that people had never had before, and that people were very grateful for it. Many said that "everyone" should experience it. People also said that it was "difficult", and that it made them realize many new things. There were also quite a few people who said that they were very happy not to be visually impaired themselves. It's tempting to say that this sentiment is missing the point - after all, the idea was not to show how "bad" life might be for a visually impaired person. However, I personally feel that the vast majority of visitors took a deeper learning from the experience than a mere aversion to being without sight.

Indeed, for an observer like me, it seemed one of the most positive outcomes was the productive interaction between people with disabilities and those visitors who were generally without any disability. After all, as one visitor put it, they depended a lot on their visually impaired guide once they were in the dark: "Before I entered the dark, I was the one with eyes, and my guide had no sight. But in the dark, he was the one with sight." And one of the guides commented that her favourite thing was being able to work together with people without disabilities. In light of the stigma often surrounding people with disabilities in Bangladesh, we were all very happy to see this slight shift in power and the resulting cooperation.

It was sad to end the exhibition so soon after it opened, and everyone involved was enthusiastic that we should do it again. The participants had a number of useful comments of their own about the whole experience, which included the following. They felt it could have been organized rather better, with better publicity (I think we admit that); that the money should have had Braille on it, to provide a solution to the existing problem of identifying different notes; and that the guides should not really be "guiding", but rather "encouraging" - so the visitors should be the ones trying to find their way with the guide behind, perhaps giving them marks according to how well they do.

We hope to do the exhibition again elsewhere in Bangladesh. Our team of participants is eager to train other people with disabilities to perform the same roles in the exhibition. We are also considering some variations on this design, which could focus on other disabilities - such as wheelchair use or deafness. So the future looks bright for 'Seeing in the Dark'.

Some Comments on 'Seeing in the Dark'-

"This exhibition to understand the blind has opened my eyes. I wish every body understand the visually impaired population." Saleem Samad/ Journalist, Bangladesh Observer

"I don't know how to express my true feelings that I felt while I was inside this room. Working in this field for a number of years, I thought that I had understood the problems faced by people with visual impairments at least to some extent! How wrong I was!" Nafees/NFOWD

"Very informative experience. A great way to make us confront the issues facing the blind in Dhaka." Anonymous visitor

"It's a very interesting and amusing programme. I enjoy the blindness and learning about how they pass their own lives. Also thanks to Zakir bhai who helped us. It's a memorable day in my life." Anonymous visitor

ANNEXURE-4

Draft of the proposed UN petition (by Minal Doshi)

Social Protection to plays a crucial role in reducing the vulnerability of all groups of the population; yet, it has found hardly a mention in the strategies to achieve all Millennium Development Goals.

The goals are a measurable set of targets to focus the efforts of the international community on achieving improvements in people's lives. Though, the overall impact of achievement of these goals is a better quality of life for people of poor countries, many of these goals seem to be completely out of reach. Even those countries, which appear to have lesser problems, certain groups will be left behind. In order to achieve the goals, various facets of human conditions need to be explored and addressed.

This is even truer for goals relating to education, health and gender equality, where issues are not confined only to their particular areas. Considering social protection as vital to reduce the vulnerability of the poor to enable access to health and education will translate into more effective achievement of the MDGs.

Social protection includes policies that provide social safety nets, social funds, labor market interventions, and social insurance (including pensions).

Social risk management (SRM) is a new conceptual framework that views social protection as a set of public measures that support society's poorest and most vulnerable members and help individuals, households and communities better manage risks.

It includes three strategies to deal with risk (prevention, mitigation and coping), three levels of formality of risk management (informal, market-based, public) and many actors (individuals, households, communities, NGOs, governments at various levels and inter-national organizations) against the background of asymmetric information and different types of risk.

This view of social protection emphasizes the double role of risk management instruments- protecting basic livelihood as well as promoting risk taking. It focuses specifically on the poor since they are the most vulnerable to risk and typically lack appropriate risk management instruments, which constrains them from engaging in riskier but also higher return activities and hence gradually moving out of chronic poverty¹.

It is with this perspective that we, the participants from countries in Asia, Africa and Europe having attended Round Table II on Mainstreaming Disabilities in

Development in Ahmedabad, India wish to bring to your notice our concern about non-inclusion of Persons with Disabilities in the Millennium Declaration as well as the Millennium Development Goals (MDGs). We agree, in philosophy, on the agenda of the MDGs and it is with this spirit, that we recommend the following:

The sheer number of Persons with Disabilities in developing and/ or poor countries makes them the largest of people vulnerable to extreme poverty and hunger. We urge the UN to acknowledge that disability is one of the key indicators of poverty

According to a UNESCO report; approximately 98% of children with disabilities in developing and/ or poor countries are out of school. Yet, no specific mention has been made of this overwhelming fact. Within the 2% who are in school, an abysmally low number are girls with disabilities. We propose due attention from the UN on the plight of this group.

Women with disabilities face dual discrimination; of being women first and then of being women with disabilities. We appeal to the UN to recognize the disability agenda in the mainstream gender issues.

The risk of death "in utero" and after birth is greatest for "high risk" children as well as those with disabilities. We consider no specific mention of this group quite disconcerting and appeal to you to safeguard their Right to Life and Living.

We, the participants, unanimously agree on the above and submit this petition for consideration and due action to ensure a rightful place for persons with disabilities in the MDGs.

Bibliography:

1The Contribution of Social Protection to the Millennium Development Goals

[http://wbln0018.worldbank.org/HDNet/HDDocs.nsf/vtlw/d2e481574dfaa17585256dc2004d5cee/\\$FILE/SPMDGs.pdf](http://wbln0018.worldbank.org/HDNet/HDDocs.nsf/vtlw/d2e481574dfaa17585256dc2004d5cee/$FILE/SPMDGs.pdf).

ANNEXURE-5

How disabled people manage in the workplace (Contributed by- **Prabha Mehta**)

Research on disabled people and employment has previously focused on the barriers to getting and keeping work, the connection between work and benefits, or policy analysis of rehabilitation, workplace disability management and retaining people in work. Little attention has been paid to how disabled people who are in employment manage to survive or indeed thrive in the workplace. This study by Alan Roulstone, Lorraine Gradwell, Jeni Price and Lesley Child explored the strategies used by disabled workers to get by in the workplace, and looked at the nature and role of support received by disabled workers. The research found that:

Disabled workers used a diverse and often complex range of strategies to thrive and survive in the workplace. There was no universally beneficial strategy that could be applied by all disabled workers. What worked for one disabled worker may be unhelpful or even risky in a different workplace. Strategies used most often included being assertive but not aggressive in asking for support, and being open about impairment, disability and barriers. In addition, a wide range of supports were used, such as moral and financial support, empathy, 'give and take', and mutual support and advice. A number of disabled workers felt that using strategies gradually was successful, because understanding the organisation first helped to develop suitable strategies.

Disabled workers needed gradual strategies in order to understand employment environments, management styles, personnel changes, corporate priorities and impairment changes.

Formal and informal support, both past and present and also both inside and outside work, was central to disabled workers' survival and their enjoyment of work. Informal or unwritten support within work was particularly important for disabled workers.

Major sources of support mentioned were colleagues, Jobcentre Plus 'Access to Work' provision, family and friends, employers and managers, organisations of and for disabled people, and trade unions. The researchers conclude that much still needs to be done to understand and respond systematically to disabled workers' needs. Despite their existing strategies and support, disabled workers want access to more structured, formalised and appropriate support.

Introduction

Previous research has established that working-age disabled people are significantly more likely than non-disabled people to be unemployed or under-employed. Since 1997, the Labour Government has emphasized welfare through work and the idea of social inclusion as being achieved through paid work.

This study explored how working disabled people get by at work. It used a national survey plus interviews and focus groups to examine how working disabled people manage in the workplace, and how they survive or thrive at work. The study quickly established the importance of strategies and support.

Strategies were defined as those ideas, decisions and plans adopted by disabled people in order to get on better at work. They were seen as ways of getting more out of work by making it more accessible and inclusive, and thus more likely for work tasks to be completed.

Formal and informal support from both inside and outside the workplace was important. Support was defined as schemes, actions, financial benefits or work changes that did not stem from the individual disabled worker. These mechanisms provided emotional, moral, practical, financial, technical, environmental and organisational support.

Key strategies

The following were some of the most important strategies used by the participants in the study in order to get on better at work.

Being assertive

Asserting your needs as a disabled worker (without being too aggressive) was noted by a number of participants.

"There is a danger of the disabled person ... ending up the passive victim of other people's ... attitudes. I believe very strongly that part of what disabled people have to do is empower ourselves. Equality is never going to be given to us. We have to assert it in a way that is positive, to be assertive and not aggressive."

This assertiveness usually took the form of workers asking for what they needed, but sometimes was about resisting job changes or unwanted developments, including promotions.

"... at the time of my appraisals she [the manager] did actually ask me if I wanted to become a property manager and I said 'no', and the reason I said no was ... you had to go round and visit the properties, which was not a practical thing for me to do."

Being open

Another commonly used strategy was being open about impairment, disability and barriers at work. The need to be open was important, as it allowed a fuller understanding of workplace challenges.

"I couldn't work in a job where I wasn't accepted for what I am ... I don't always handle things 100% well, but I do have a mental health history that sometimes I need things that are not conventional."

Using information and communications technology

Information and communications technology was seen as improving working life for some disabled workers. This included new, computer-based technologies as well as established technologies such as telephones and faxes. A worker with a visual impairment commented on his use of the telephone:

"I use a telephone more than other people do ... maybe it actually puts me at a slight advantage. I don't always pick up on conversational cues and therefore I will leap in. But on the telephone we are very much working on audio cues and therefore that evens things out."

Taking things slowly

A small number of disabled workers felt it was better for them to adopt a gradual but planned strategy. They saw it as important not to be too precipitate in asking for workplace changes but to build up workplace relations before asking. This helped them understand employment environments, management styles, personnel changes, corporate priorities and impairment changes:

"Well if I was starting a new job I think I'd try to be as independent as I could for a start, however hard it was, then I think people would start offering to do things for you if they can see the things you are struggling with, or if you actually have to ask, would you mind doing this for me, then I think that would probably find its own level."

Supporting disabled workers

Support was vital to disabled workers. Some support came unprompted, over time and often at no cost. Support came from both inside and outside work, and could be formal or informal.

Moral and financial support

This type of support was usually provided by friends and family, sometimes before taking up the current employment. The following is what a worker with a learning difficulty said about the support provided by his father:

"He gives me a certain amount each month ... he's generously paid for a computer that I now use ... at home ... because it was clear I had to learn how to use a computer for the work that I do here, so it was to help me with work here and to gain confidence using a computer generally."

Empathy

Empathy was most commonly found among other disabled people, particularly colleagues. Empathy and acceptance of difference were seen as very important. A worker with a learning difficulty provided an example of this:

"Everybody said that the Forum [an organisation of disabled people] was definitely needed and the reason is for solidarity. Basically as individuals it's very easy for society to put us down, and it's only when we are together working collectively that we get the strength to say 'no'."

'Give and take'

This approach to support was used most often with colleagues. Mutual support and advice are important for all workers, but disabled workers felt that it was crucial in their daily work. One worker noted that he was given leeway about completing some tasks, and made up for it when he felt able to:

"If they pick up on that I'm not feeling 100% they'll say 'take your time, do what you want to, you don't have to knock yourself out'."

'Access to Work'

A key type of formal support reported by disabled workers was the 'Access to Work' scheme operated by Jobcentre Plus. There were problems in the speed and consistency of provision, but nevertheless the scheme played a key role in workplace support.

"For example, the office that I have at the moment had sash windows in it, which I can't use, and the university has replaced them with a window which opens and closes by turning a little handle. It collaborates with the 'Access to Work' people ... they've provided me with a computer that I use at home."

Support outside work

As well as support at work, some disabled workers looked outside for help or advice. This assistance ranged from drawing on the moral support of friends and family to seeking ergonomic, technological, medical and psychological support.

"I have always needed to have ... not exactly deaf support ... I have always managed to find a group of people or it might be at home, partners, friends who actually nourish me as a whole person and that has been quite an important strategy."

Conclusion

These brief insights into the strategies and support mechanisms, which allow disabled people to survive and thrive at work could help to inform and improve employment practice and support services. Some key practice and policy lessons also came out of the study.

Disabled workers adopted a sometimes-complex range of strategies. Although there was no single strategy that all disabled people could identify, some recurring messages came from the research. The work context and culture, length of time in the workplace and the presence of other disabled workers were all important factors in deciding on how to make the most of work.

Disabled workers used a very wide range of gradual and non-predictable support. This makes such support difficult to formalise or reproduce. Much support was the result of unwritten 'custom and practice' which sat between formal and informal support. However, it was clear from the study that there is scope for greater and more systematic support.

It was felt that policy-makers, particularly the Department for Work and Pensions along with the Jobcentre Plus agency, should be aware of the pivotal role of the 'Access to Work' scheme for disabled workers. However, despite its key importance, most users noted weaknesses in this scheme. These included delays in assessment and provision, lack of knowledge and skills concerning a range of impairments and barriers, difficulties in establishing funding partnerships, and the limits of personal assistance provision.

The researchers conclude that the study has implications for employers, employers' forums and trade unions. Employers should be aware that, despite strategies and support, disabled workers want access to more structured and formalised support. There is still a long way to go in understanding and responding systematically to disabled workers' needs. Trade unions, although mentioned by a small number of workers in the study, were seen as the final rather than the first option in seeking support.

Messages

For disabled workers:

- Be assertive not aggressive;
- Accept yourself for who you are;
- Be confident in asking for support;
- Be informed about your rights;
- Be open and up front.

For colleagues of disabled workers:

- Do not make assumptions about disabled workers;

- Be supportive but not overbearing;
- Attend disability equality training.

For employers and managers:

- Disabled people are not a 'special case';
- Ask disabled workers if their needs are being met;
- Be aware of and allow flexible working;
- Encourage mutual respect among workers;
- Be well informed about support options.

For Jobcentre Plus:

- Be better informed about the range of disabled workers' needs;
- Be consistent and equitable in provision;
- Be responsive and flexible;
- Share the experiences of the users of 'Access to Work';
- Look at more impartial means of support.

About the project

The research was undertaken through Breakthrough UK Ltd and completed in October 2002 by a commissioned project team of four disabled people: Alan Roulstone (University of Sunderland), Lorraine Gradwell (Breakthrough UK, Manchester), Jeni Price (Equality Associates, Brighton) and Lesley Child (freelance).

The study used a national screening survey of strategies and support, which included workers with physical and sensory impairments and also people with mental health problems and learning difficulties. This was followed by interviews and focus groups with 33 disabled workers. Access issues were discussed at all key stages of the research, and different ways of working were offered to facilitate full participation in the study. The study aimed to place the voices of disabled workers at the heart of the research findings.

How to get further information

Breakthrough UK Ltd can be contacted at Aked Close, Ardwick, Manchester, M12 4AN, tel: 0161 273 5412, fax: 0161 274 4053, minicom: 0161 273 5727 (+ answerphone).

The full report, *Thriving and surviving at work: Disabled people's employment strategies* by Alan Roulstone, Lorraine Gradwell, Jeni Price and Lesley Child, is published for the Foundation by The Policy Press (ISBN 1 86134 522 4, price £13.95).

Responsiveness is the key to success - and to survival...thats why, I am the sum total of the feedback I have received from you.