

Prevention and early detection of disabilities

- Surveys, investigations and research shall be conducted to cause of occurrence of disabilities
- Various measures shall be taken to prevent disabilities. Staff at health Centre shall be trained to assist in this work.
- All the Children shall be screened once in a year for identifying disabilities.
- Awareness campaigns shall be launched and sponsored to disseminate information.

Employment

1. 3% of vacancies in government employment shall be reserved for people with disabilities, 1% each for persons suffering from :

- Blindness or Low vision
- Hearing Impairment
- Locomotor Disability & Cerebral Palsy

2. Suitable schemes shall be formulated for

- The training and welfare of persons with disabilities
- The relaxation of upper age limit
- Regulating the employment

3. Government Educational Institutes and other Educational Institutes receiving grant from Government shall reserve at least 3% seats for people with disabilities.

4. All poverty alleviation schemes shall reserve atleast 3% for the benefit of people with disabilities.

5. No employee can be sacked or demoted if they become disabled during service, although they can be moved to another post with the same pay and condition. No promotion can be denied because of impairment.

Social Security

- Financial assistance to non-government organisations for rehabilitation persons with disabilities.
- Insurance coverage for the benefit of the government employees with disabilities.
- Unemployment allowance to people with disabilities registered special employment exchange for more than a year and who are placed in any gainful occupation.

"The Persons with Disabilities (Equal Opportunities, Protection of Full Participation) Act, 1995"

"The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995" has come into force on February 7, 1996. This is an important landmark and is a significant step in the direction of ensuring equal opportunities for people with disabilities and their full participation in the nation's building. The Act provides for both preventive and promotional aspects of rehabilitation like education, employment and vocational training, job reservation, research and manpower development, creation of barrier-free environment, rehabilitation of persons with disability, unemployment allowance for the disabled, special insurance scheme for the disabled employees and establishment of hostels for persons with severe disability etc.





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Editorial

"Towards an inclusive, barrier free and right based society"

The term 'disability' has been defined in many ways. It includes terms such as 'impairment' and 'handicap'. The WHO definitions do not take into consideration the social perspective. The social model defines disability as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.

On paper, there is an impressive agenda for protecting and promoting the interests of the disabled. The ground reality, however, is very different. Various schemes have been offered for the welfare of the disabled population, but little effort has been made to publicize them. Government support for the disabled in the form of various laws and acts such as The Rehabilitation Council of India Act 1992, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995, The National Trust Act 1999, have been long in coming and is still inadequate.

The PACS programme through its intervention projects has started demonstrating a visible reach out for sensitization of CSOs to integrate activities related to awareness creation on rights of the disabled. Among the various measures, PACS programme aims at promotion of livelihood options for meaningful employment. It is in the process of strengthening efforts to empower the disabled with knowledge through trainings and through sensitization, awareness generation and networking with the donor agencies, development sector, government agencies and the corporate sector and also on accessing the Govt. facilities. Role of media and communication was also addressed as a means of highlighting disability issues.

This edition of the newsletter takes a critical look at the efforts in mainstreaming disability, for creating an inclusive, barrier free and rights based society.

Kiran Sharma

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Mainstreaming Disability - Government's Perspective

□ T.D. Dhariyal*

Introduction

The corner stone of the Constitution of India is to secure for all its citizens including persons with disabilities, the fundamental rights. Recognising that people with disabilities would need special legislation to enable them to secure these fundamental rights and more, Government of India enacted the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, Rehabilitation Council of India Act, 1992 and National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, Act, 1999. These enactments are directed to achieve an effective shift from a charity and welfare based approach to a rights & development based approach. The basic philosophy is, "All Human Beings are born free and equal in Dignity and Rights". Mainstreaming persons with disabilities in all walks of life is, thus an inevitable consequence. Its time has come.

The Persons With Disabilities Act and Mainstreaming Disabilities

India is a signatory to the Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Region, which was adopted in the meeting convened by the Economic and Social Commission for Asia and Pacific (ESCAP) held at Beijing from 1st to 5th December 1992. Towards implementation of the proclamation, Indian Parliament enacted the Persons with Disabilities Act, 1995. The enactment of this comprehensive legislation is also the outcome of a growing consciousness about the rights of persons with disabilities and demonstration of exceptional skills & capabilities by many of them. It shows the commitment of the government to ensure human rights to all the citizens, equalisation of opportunities and an inclusive society. The advocacy groups in the country played a critical role in pushing it through.

The Act encompasses almost every key issue right from prevention, early detection of disabilities, mainstream education in an appropriate environment, non-discrimination, barrier free environment,

employment, sustainable income generation, manpower development, affirmative action, social security. It has put in place the mechanism for evolution of comprehensive policies on disability both at the Centre and in the States, their execution, monitoring and quasi-judicial redressal of grievances of persons with disabilities.

Prerequisites for Mainstreaming

Empowerment of persons with disabilities is the basic condition on which will depend their effective mainstreaming and inclusion. A combination of actions by the Government, the civil society and the NGOs will help in achieving the desired outcomes. The actions are needed in the areas of early detection of disabilities and intervention (medical rehabilitation), accessibility of built environment, information and communication, positive shift in the mindset of people including persons with disabilities about their strengths (social rehabilitation), inclusive education (educational rehabilitation), vocational training, opening up all possible employment opportunities (vocational rehabilitation). It is expected that when these four areas have been addressed, the negative effect of a disability on a person is minimised and that he can realise his maximum potential. These areas can be facilitated by favourable legislation. All the stakeholders therefore, need to use persons with Disabilities Act and the other two Acts and the available infrastructure for the benefit of persons with disabilities to facilitate their full participation.

Disability Statistics and the Challenge

Number of Persons with Disabilities

As per the National Sample Survey Organisation (NSSO), Govt. of India (NSS 58th round, July - December 2002), the number of persons with disabilities in the country was 18.49 million, which formed about 1.8% of the total population. About 8.4% and 6.1% of the total estimated households in the rural and urban areas, respectively had at least one person with

disability. The prevalence of locomotor disability was the highest in the country at 1046 in rural and 901 in the urban areas per 100000 persons followed by visual impairment and hearing impairment. More than 75% of the people with disabilities were in rural areas where the incidence of poverty is much higher than in the urban areas.

Where Do We Stand?

Education

Education is perhaps the most important prerequisite for mainstreaming persons with disabilities. As per NSS 58th round, about 45% of the persons with disabilities were literate and only 9% completed secondary & above level of education. The enrolment ratio per 1000 persons with disabilities of age 5 - 18 years in the ordinary schools was 475 in rural areas and 444 in urban areas. About 11% of the children with disabilities of age 5 - 18 years were enrolled in special schools in urban areas whereas it was 0.06% for rural areas (NSS 58th round, pp. 20). This shows very low level of appropriate education facilities for children with disabilities in the rural areas, yet greater degree of integration in schools, even though it may be due to unavailability of special schools. Only 15 to 35 persons with disabilities out of 1000 completed any vocational training.

As per NIEPA's 'Elementary Education in India, Analytical Report-2004', in 24 states and one UT covered under District Information System for Education, total enrolment of children in Classes I-VII/VIII was 143535720. The number of children with disabilities was 1758483 i.e. 1.2% of the total. Total schools up to Hr. Secy. were 931471 of which 811520 were in rural areas, which formed 87%. 3.8% of the schools (35449) were without buildings and 91.7% of them (32507) were in the rural areas. Therefore creation of massive accessible educational facilities with appropriate teaching learning material for children with disabilities especially in the rural areas must be given top priority.

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Participation in Economic Activities

26% of the persons with disabilities in rural and 24% in urban areas were employed (NSS 58th round, pp 20). 70% of them in rural areas were engaged in primary sector, whereas in urban areas, tertiary and the secondary sector at 87% played dominant role in employment generation for persons with disabilities (NSS 58th round, pp. 21 & 22). It is obviously because of the dominant agrarian nature of the Indian economy. The huge gap between the level of participation in economic activities of persons with disabilities and employment level in general must be bridged.

According to the advocacy groups in the country and the international agencies, the disabled population in the country is much more than 2% as even in Europe, North America, Australia, etc it is estimated to be between 10% and 20%. 35% to 45% of the disabled people in European countries are reported to be 65 years old or more. Adoption of similar criteria in India would certainly give a much larger figure. In fact, the data on disability are inadequate and inaccurate across the globe because of adoption of different definitions of disabilities, complexity, and multi-faceted relationship that the concept of disability represents between an individual and his or her environment and inadequate efforts by concerned agencies. For example, an individual who is limited in his or her ability to function in one environment may not be limited when components of that environment are modified.

Case for Mainstreaming Persons with Disabilities

Equal share in development outcomes

Mere size of even the accepted number of persons with disabilities demands their inclusion and mainstreaming in all aspects of life i.e. health, education, training, employment, recreation by enabling them to access the facilities. Such a huge number of citizens cannot be excluded and denied the opportunities that have been thrown open by the buoyant Indian economy that registered a growth rate of 8.5% in 2003-04 and nearly 8% during 2004-05 (Economic Survey - 2004-2005 pp. 1). The country's Human Development Index ranking has also improved from 132nd out of 173 countries

in 1997 to 127th out of 176 countries in 2002 (UNDP Human Development Report 1999 & 2004/E.S. 2004-2005 pp. 224). The persons with disabilities too have equal share in all the development outcomes.

Equally important is to note that persons with even severe disability have contributed as much as their non-disabled counterparts, given equal opportunity and the enabling environment. Many are amongst the most successful political leaders, administrators, financiers, businessmen, teachers, craftsmen, artists, musicians, etc.

Economics of Mainstreaming Persons with Disabilities

Rehabilitation of persons with disabilities and their mainstreaming is not charity. It has commercial value for the individual, the community and the nation as a whole. Often people think that rehabilitation of people with disabilities is only a cost to the exchequer, the society and the family. It is beyond the scope of this article to dwell upon the cost-benefit analysis of rehabilitation, as the quantity and the quality of rehabilitation services are dependent on a large number of factors including the socio-economic development of a nation. It will suffice to say that the expenditure on rehabilitation of persons with disabilities or for that matter, any segment of the society is indeed an investment. It adds to the national income as efficiency, productivity, and longevity of the disabled person after rehabilitation get enhanced. The family saves on the foregone income on account of the time spent on care of disabled member of the family. It also reduces the liability of the government for social security. The direct benefits alone to the economy are far more than the cost of rehabilitation.

The net benefit to the economy as a result of rehabilitation of persons with disabilities can also be explained with the help of a very crude and simple example, which is based on the amount of social security in the form of disability pension.

Persons with disabilities of age 19 and above in 2002 was 124,38,100. 32% of them which is equivalent to 8.38 million (83.83 lakh) were unemployed (NSS 58th Round, Appendix-A, page A-3 and A-229). Assuming that 20% of them do not require social security, there will still be 5.9 million (58.96 lakh) persons with disabilities available and willing to undertake some economic activity. If

disability pension @ Rs.200/- per month per disabled person is given for 20 years, the cost of the pension alone would be Rs.1180 million (Rs.11800 lakh) per month or Rs.14160 million (Rs.141600 lakh) per annum or Rs.283200 million for 20 years at current value of Rupee. Even if small amount of this huge money is invested on vocational training and some of the people with disabilities are engaged in some economic activities, they would add to the national income. They will also create demand for caregivers, escorts, aids and appliances, equipment, etc. and also release the members of their families (parents, siblings, and spouse) for some economic activity.

Therefore, it makes good economic sense to invest in rehabilitation of persons with disabilities and include them in the workforce. Additionally, mainstreaming of persons with disabilities will result in social benefits at individual, family community, national and at global level.

Poverty and Disability

Majority of the persons with disabilities are amongst the poorest of the poor and poorer people are more prone to disabilities. A disabled person also needs more resources for his or her maintenance as compared to a non-disabled person of the same status. Thus, the former with the same level of income is able to afford a lower standard of living. Conversely, for maintaining equal standard of living, a person with disability will need more resources than a non-disabled person. This makes a very strong case for raising the level of poverty line in respect of persons with disabilities other things being equal. Otherwise, a large number of deserving persons with disabilities would not be able to access the facilities meant for people below poverty line.

Government of India's Policy and Efforts

Government of India's policy is one of social and economic inclusion of persons with disabilities and creation of enabling environment for equalization of opportunities. Ministry of Social Justice & Empowerment, the nodal Ministry, undertakes activities to empower persons with disabilities to facilitate their participation through its own organisations and through NGOs by extending grants to

them for special education, fitting of aids and appliances, vocational training, manpower development etc. State Governments also implement similar schemes.

The National Policy on Disability, which has been approved recently is a major effort of the Government to realise the mandate of the Persons with Disabilities Act.

National Handicapped Development Finance Corporation under the Ministry has schemes for extending loans to persons with disabilities/parents of mentally retarded persons to promote self-employment at low rate of interest.

The Persons with Disabilities Act, 1995 has provision for at least 3% reservation of vacancies in jobs in Government establishments and seats in admissions in educational institutions.

There are special components for inclusion of children with disabilities in regular schools in Sarva Shiksha Abhiyan (Education for all) and Integrated Education for Disabled Children (IEDC) schemes of Ministry of Human Resource Development. The Ministry is in the process of finalising Inclusion in Education of Children and Youth with Disability (IECYD) which is holistic in nature and will take care of appropriate education of persons with disabilities from pre-school to higher education at university level. The availability of screen reading software is helping the print disabled in accessing higher education.

Ministry of Urban Development has amended the building bye-laws to ensure accessibility for persons with disabilities to the built environment. The State Governments are also doing so. This is improving the accessibility, though slowly, as the constructions are old. These measures are promoting mainstreaming, greater participation and economic empowerment of the persons with disabilities.

The Act also provides for 3% reservation for persons with disabilities in various Poverty Alleviation Schemes such as Swarnajayanti Gram Swarozgar Yojana (SGSY), Sampoorna Grameen Rozgar Yojana (SGRY), Swarna Jayanti Shahari Rozgar Yojana (SJSRY), Rural Housing - Indira Awaas Yojana (IAY) etc. In addition,

Government of India will also implement National Rural Employment Guarantee Scheme to ensure atleast 100 days of guaranteed wage employment in every financial year to every household (ES 2004-2005 pp. 228-229).

Full utilisation of 3% reservation under all the above schemes has not been achieved apparently because the programmes/projects are not inclusive enough for persons with disabilities to undertake the activities under the schemes. Often, small modifications at the work place, accessible toilets, transport, roads, positive attitude can improve their participation. Their heterogeneity may also require tailor made programmes to suit their skills, potential and special needs. There is need to promote accommodation and adjustment of the society and the development projects to the needs of persons with disabilities.

The Persons with Disabilities Act, 1995 is a powerful tool to mainstream disabilities. The actions emanating from the Office of Chief Commissioner and Commissioners, Disabilities of the States directed at implementation of various provisions of the Act have helped fight discrimination, provide employment including in senior positions, admissions in general and technical courses and make places disabled friendly. These actions and orders are also creating awareness and confidence in people with disabilities across the country.

The Role of Civil Society

Implementation of socially beneficial Acts, schemes, and programmes is very difficult without involvement of the civil society and a healthy conversance and coordination between them and the Government functionaries. In the disability sector, the participation of the persons with disabilities themselves and their parents is also of paramount importance. For an effective and meaningful inclusion and mainstreaming of persons with disabilities, a multi-pronged and coordinated effort is essential. It is also important that the persons with disabilities are included not only in disability related issues or activities, but also in all other matters.

Disability Scenario in the Pacs Districts

Sizeable number of persons with disabilities in the PACS districts also makes a very strong case for developing and

implementing inclusive programmes and projects to enable their participation. Possibly, they are the poorest of the poor and therefore their empowerment and participation will serve the purpose of PACS programmes in real sense of the term. The task may seem difficult, but this challenge if successfully taken, can change the lives of so many and turn them into assets and contributors to the nation's economy.

Conclusion

Mainstreaming disability should be viewed as an economic and social necessity in recognition of the rights of persons with disabilities. If they are given the equal opportunity and enabled to participate, their rehabilitation will be driven by market forces. They have to be treated as contributors to the nation's economy as rest of the citizens. Coordinated and convergent actions by the Government agencies and the civil society will play critical role in mainstreaming disability by developing and implementing inclusive projects/programmes in the areas of health, education, employment and accessibility.

References

1. Ministry of Statistics & Programme Implementation, Govt. of India (December 2003), NSSO, National Sample Survey, 58th Round (July - December 2002).
2. Census 2001, Govt. of India.
3. Economic Survey, Govt. of India, 2004-2005.
4. Rehabilitation Council of India, Ministry of Social Justice & Empowerment, Govt. of India, 2004, Summit of the Mind - All India Cross Disability Convention.
5. Obert P. Ndawi (2001), A paper on "The Role of Legislation in Facilitating CBR in Zimbabwe" presented in the Conference on CBR - A Participatory Strategy in Africa, published by University College London, Centre for International Child Health, London.
6. EU, Mainstreaming Disability within EU Employment & Social Policy-europa.eu.int/comm/employment_soci al/soc-prot/ disable/dresden/workpaper_en.pdf
7. Rangasayee R., (1992), Economics of Disability Rehabilitation.

Livelihood Options for the Persons with Disabilities[*]

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Disability, in India, has emerged as an important issue of public policy discourse. There are three important legislations that translated the discourse into actual policy namely - the Rehabilitation Council of India Act, 1992 amended in 2000, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, and the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1998. The PWD Act remains the central legislation with respect to disability. The Act entrusts the State/s to set up mechanisms - primarily institutional - for implementing its provisions. Apart from the public institutions supported by the State, there are other formal and informal institutions like the NGO (Non-Government)/DPO (Disabled Peoples' Organization) sector, as well as family, household and self-help groups. These formal and non-formal institutions together translate the act into reality.

Apart from the disability legislations, there are several other development policies and programmes that should ideally be inclusive of people with disabilities. These policies and programmes address issues and concerns like education, employment, livelihoods, access to services, information, health care etc. that affect disabled population equally. In the past few years, the partnership between government and non-government organizations has increased in converting development programmes into reality.

Broadly speaking, policy makers, government and non-government agencies, donor institutions and civil society organizations have either looked at disability as a charity, medical and rehabilitation issue and, thus, relegated their responsibility to the welfare agencies of the government or treated it with neglect. There are scores of development agencies in India that are actively working in the area of income-generation and

livelihoods with no focus on persons with disabilities. People with disabilities are conspicuous by their absence in the public works programmes. Their definition of work is too narrow and includes only heavy physical work which people with disabilities may find difficult to engage in. This article has attempted to look at the connection between disability, poverty and challenges that impede access to livelihood options and, thus keep people with disabilities engaged in a vicious cycle of penury.

Establishing linkages between disability and livelihood programmes:

Although it may sound clichéd and indulgence in rhetoricism that disability is likely to be present in the poorer sections of society and that disabled people are poorest of the poor owing to their disability, yet the fact remains that little has been done to address the issue of disability and poverty. In the context of developing countries, Elwan's[†] observation confirms that disabled people have lower literacy and income levels. "They are more likely to have incomes below poverty level, and less likely to have savings and other assets than the non-disabled population...In addition to the income-related factors, additional costs resulting from the disability; and marginalization or exclusion from services and/or social and community activities can also make disabled people or their families worse off. Additional costs include those for extra medical expenses, specialized equipment and services, etc, and costs incurred by care providers"(iv). Citing a study conducted in India by Harris White, Elwan shows that disabled peoples' expenditure in India on the direct cost of treatment and equipment varied from 3 days' to 2 years' income, with a mean of 2 months (iv).[‡] Disabled people are, thus, caught in a vicious circle of poverty and disability which is acute in the case of women with disabilities owing to the discrimination they face on account of their impairment and gender.

In the context of livelihoods programmes, it is observed that there are no public works programmes that are disability targeted or inclusive of disability. Concerns of disabled people have remained outside of the purview of all major policies whether those of health, or education, employment, banking etc. Even the latest National Rural Employment Guarantee Scheme Act 2005 has failed to acknowledge the existence of this identity group by keeping the definition of work narrow and including only able-bodied people in the ambit of employment.

Barriers to accessing livelihoods options

a) Architectural Barriers: It has been reiterated over and over again that development of people with disabilities hinges upon removal of barriers to physical environment. If people with disabilities are to enjoy their rights to full and equal participation, the foremost thing that all key stakeholders will have to ensure is to provide access in all their programmes. In the context of livelihoods and social safety nets, Sophie Mitra defines Access as:

a means of approaching or entering a place and as an opportunity or a right to use something or approach somebody. Accessibility is the time, effort and cost, in brief the ease, with which a good, a service or a facility can be reached or used. Accessibility is closely linked to both poverty and disability. It is commonly acknowledged that a lack of access is an important contributing factor to poverty given that it limits the opportunities that people have to improve their economic well-being. Having a disability creates accessibility challenges, therefore accessibility is one of the mechanisms whereby disability can lead to poverty. The nature of these challenges varies depending on the severity and the

type of disability (physical, sensory or mental). As tools to reduce poverty, safety nets need to be accessible to persons with disabilities. If they are inaccessible, social safety nets contribute to exacerbating inequities between persons with and without NGOs working in human rights, gender, livelihoods, micro-credit, tribal issues, dalit issues have not brought disability on their radar screen also. Disability is not an indicator of measuring development and there is no inter-sectoral targeting on disability in the development/donor agency sector.

b) **Social and Communication Barriers:** Mitra also talks about removal of social and communication barriers. In her words:

Besides the need for information in alternative formats, illiteracy constitutes another barrier to program access for persons with disabilities. Disability is indeed associated with illiteracy in developing countries for different reasons, including exclusive educational systems. Therefore, program staff may need to use person centered methods to communicate with poor communities. In addition, there may be a lack of sensitivity among program personnel about disability matters, including confused perceptions on persons with disabilities as medical cases rather than as persons with entitlements. An information campaign and training on disability, as well as the employment of persons with disabilities among the staff of the advice and delivery centers, would serve a useful purpose. It would raise awareness and foster an attitude of respect for the rights of persons with disabilities and promote an image of persons with disabilities as capable and contributing members of society. (26).

Easy access reduces the gap between disability and poverty and is, thus, directly

linked to economic empowerment of people with disabilities.

Mainstreaming people with disabilities in livelihood programmes:

Although, because of certain specific needs of people with disabilities it is important that a targeted approach be adopted, through quotas etc., to include people with disabilities, it has been observed that a twin-track approach is the best where targeted programmes as well as inclusion in mainstream development activities and programmes is simultaneously ensured. While analyzing the pros and cons of mainstreaming and targeting, Mitra suggests that that "Mainstreaming should take place with a pinch of targeting" (38). She has also given examples as to how livelihood programmes can address and include disability concerns. Since one of the key concern area of PACS and its partners is livelihoods and income-generation programmes, it would be extremely useful to quote Mitra's strategy here:

One way is to establish linkages between livelihood programs and disability targeted programs such as assistive devices, personal assistance and vocational rehabilitation programs. Conditional in-kind transfers for assistive devices or personal assistance can provide an incentive to persons with disabilities to participate in livelihood programs. The person is given a free or subsidized assistive device or personal assistance if she agrees to participate in livelihood programs....This is particularly relevant for micro-finance programs that sometimes require applicants to demonstrate business management skills or work experience. For persons with disabilities who may have not been able to access employment or schools in the past, the participation in a vocational rehabilitation program could be used as a substitute for work experience or education required. (29).

Adoption of this strategy will go a long way in reducing poverty among the disabled people who come from the

poorest of the poor sections of society in the developing world.

Works Cited:

Bhambhani, M. The Role of Institutions in Delivering Services to Disabled People in India: Key Issues, Bottlenecks and Recommendations for Policy Change. Unpublished Background paper on Institutions with field work conducted in Rajasthan and Karnataka. March 2005.

_____. From Charity to Self-Advocacy: The Emergence of Disability Rights Movement in India. Unpublished thesis submitted as requirement for the degree of Master of Science in Disability and Human Development in the Graduate College of the University of Illinois at Chicago, 2004.

Elwan, A. Poverty and Disability: A Survey of the Literature- background paper for WDR 2000/2001 and as part of the Social Protection Unit's research on the economic consequences of disability.

Mitra, S. Disability and Social Safety Nets in Developing Countries. Social Protection Discussion Paper Series, No. 0509. Social Protection Unit, The World Bank: May 2005.

[*] This paper is an excerpt from the key position paper on disability written by me for PACS in November 2005.

[†] Elwan, A. (1999). Poverty and Disability: A Survey of the Literature - Background Paper for WDR 2000/2001.

[‡] Report on DSA Poverty Study Group meeting: information from Harriss-White on a recent survey, cited in Elwan. Meenu Bhambhani Programme Officer

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Employment for People with Disability

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Introduction

In the rapidly bewildering market economy persons with disability have been bemused not because of the result of their disability because of the social perception towards them. The state throughout the various stages of its revolution has never recognised the biological and social needs of PWDs with regard to their able-bodied counterparts. The family of PWDs, neighbourhood and various other social institutions have always look down upon the potentials of PWDs and treated them as a liability on he society and a responsibility of state.

Disability is deeply linked with poverty as its cause and consequence. PWDs have never been looked with regard to the labour force in market economy. With the passage of legislation and the International pressures on the corporate houses for the implementation of corporate social responsibility. There has been a perceptible change for last one decade.

Since late 90's many organisations across the Indian public and private sector have identified the meaningful employment of People with Disability as a key concern. Organisations like the Confederation of Indian Industry have a broad approach covering "awareness and sensitisation in the work place and the community, making work places accessible for disabled people and promoting employment of disabled people".

For many of these organizations the opportunity lies in solving many problems at a single stroke. The employment of PWDs would, amongst other things:

- Tap into new supplies of labour for

public and private sector - there are 7 million employable disabled people in India waiting to work;

- Create new markets for new classes of employee an economically independent workforce of PWDs would create demand for new products e.g. disabled friendly mobile telecommunications and computer software;
- Reduce the strain on public sector and welfare studies across the world have proved that disability is linked with poverty, disability is both the cause and consequence of poverty; and Reduce expenditure on training for trainings sake an opportunity cost saving for NGOs and the private sector.
- Thus, the development towards the employment of PWDs is rooted in issues of economics and market solutions. The most sustainable approach is market driven removing welfare through employment and increasing economic output.

Moreover, the goal is a labour market which is accessible to PWDs, seeks no subsidy or allowance for the supply of labour with disability and no discriminatory pricing in its remuneration. This allows workers with disability to compete in a free labour market.

It is self evident that effective employment for PWDs is a function of education and appropriate training. However, these are outside the scope of this note.

Employment outcomes. Statistics show that less than 1% of persons with disability are in the work

force of the country. What are the choices for the employment of PWDs?

1. Self employment

The most participatory approach to the employment of PWDs and the one which most empowers PWDs is self employment. Self employment opportunities and, in particular, the availability of commercial loans and micro finance should be available to PWDs across society.

Some ideas of levels of finance are as follows:

- Typically NGOs will give small business initiatives by PWD nominal rupee amounts unsecured;
- Micro finance schemes start at around 20,000 rupees;
- Micro finance and credit schemes give loans, unsecured, up to 50,000 rupees;
- Micro finance and credit schemes give maximum loans, secured, of around 200,000 rupees;
- Repayment tends to be up to 5 years after a reasonable period of non payment; and Interest rates vary but as an example ICICI Bank provides funds to Micro Finance Institutions (which onward lend to individuals) at around 8%.
- The Small Industries Development Bank of India (SIDBI) estimates that their rate of recovery under micro credit programmes is as high as 98%. A remarkable rate which has led to the emergence of private micro finance.
- The UN has examined micro finance in India:

"There are several Micro-Finance implementing organisations which provide small loans in India. Some of them have successfully expanded their services to thousands of borrowers. Given the fact that most of these borrowers would not have had access to formal financial institutions, that many of the borrowers utilise the loans to enter and/or expand their informal sector micro enterprises, and that the informal sector continues to be an important source of livelihood for many poor people, these Micro Finance Organisations (MFOs) may very well have had a major impact on improving the living standards of millions of poor persons as well as on promoting economic growth."

2. Open employment Government

Indian law says:

"Appropriate governments shall:

- (a) Identify posts, in the establishments, which can be reserved for the persons with disability;
- (b) At periodic intervals not exceeding three years, review the list of posts identified and update the list taking into consideration the developments in technology" and that "Every appropriate government shall appoint in every establishment such percentage of vacancies not less than 3 per cent for persons or class of persons with disability of which 1 per cent each shall be reserved for persons suffering from:
 - (i) Blindness or low vision;
 - (ii) Hearing impairment;
 - (iii) Locomotor disability or cerebral

palsy, in the posts identified for each disability"

There are three problems that arise in this arena:

Reservations fall below the 6-7% of the population with a disability;

there are few governments taking a proactive approach to combining training with these reservations; and the targets are some way off and there is little transparency on their fulfillment.

Continuing effort and emphasis needs to be placed by the Indian government on delivering these targets.

3. Open employment - Private Sector

Over and above legislation on access and other general encouragement for corporates to recruit labour from PWDs, progress appears to be more push than pull.

The following issues are apparent: Vocational training that highlights and is linked to a job opportunity and that is tailored to an individual's needs is the most effective form of training, this includes development and modifications to technology this is not the norm whilst too much vocational training by NGOs lacks quality and relevant and up to date technology;

Custom built workstations are a new trend corporates e.g. BHEL maintain dedicated and disabled friendly workstations and work areas where PWDs can work and are remunerated per unit;

Assistance to disabled persons in getting gainful employment is available either through the special cells in employment exchanges or through special employment exchanges for disabled persons. Upto 100% financial assistance is provided in

the case of special cells, and 80% in the case of special employment exchanges of State government and Union Territory administrations. Placement and recruitment services are also provided by NGOs. These need support from state and government resources to interact with corporates.

The labour market needs to recognize that PWDs working together or job sharing is an effective way of nullifying disability e.g. a person with hearing impairment working with a person with low vision.

4. Sheltered employment

Sheltered employment (often combined with accommodation) has been the preferred method of providing meaningful employment opportunities for PWDs by NGOs. However, many of them struggle to manage costs run effective sales and marketing programmes and attract entrepreneurial management. Consequently they struggle to compete for private sector and government orders despite preferential pricing on contracts.

At present there is no evidence that an NGO has managed to transform sheltered employment into a profit making, competitive or free market vehicle closer to starting a small business. However, a vehicle like this, which would be subject to the disciplines of the market, would represent a powerful economic engine for the labour market of PWDs.

For reducing poverty amongst the PWDs. It is important that the state, NGOs and all other social institutions start looking at persons with disability as normal human beings with the reservoir of potentials to be meaningfully employed at parity with their able bodied counterparts. PWDs will also have to take steps to significantly contribute in the economy of the state leading to change in their status from a tax liability to a tax payer.

Accessibility Access Audit as a Tool

Every individual including Persons with Disabilities (PwDs) have the equal right to live with dignity and grace; are citizens, community members, students and employees and have the same capacity to be productive citizens, given equal opportunities. The Persons with Disability Act, 1995 provides for incorporation of barrier-free features in built infrastructure both inside buildings & outside and in the transport sector. The promotion of Barrier Free Environment (BFE) leads to inclusion of PwDs in the mainstream society.

The built environment should be designed in a manner that includes all groups of people irrespective of age, size and gender. No group of people should be deprived of full participation in and enjoyment of the built environment or be made less equal than others due to any form or degree of disability. Accessibility means:

- a. It should be possible to safely reach/ enter & exit all places and
- b. Make use of all facilities.

"Barrier" the word itself means - a manmade creation to isolate or obstruct. Common barriers faced in day to day life are:

- Level differences & mobility,
- Orientation & Communication (Orientation clues for persons with vision impairment and information & communication techniques for persons with hearing impairment),
- Access to information and
- Transportation

Who benefits from a barrier free environment?

Every one including you and me!

- People with reduced mobility like senior citizens, families with young children, pregnant women, people with temporary ailments, wheelchair users etc. Moreover, one should realize that each and every person, at some stage of life, might cross barriers and require BFE.
- Low sighted and vision impaired persons.
- Hearing impaired persons.
- People with intellectual disabilities.

Myths and Realities:

Many also have an impression that barrier free environment is an expensive affair but it is not so. In fact, it is cheaper, if one considers long-term benefit. There is another misconception, it seems only wheelchairs users' need accessible environment and making a ramp (often it is a slope) can solve all the problems. There is nothing more wrong than this. "Special provisions for 'special' people segregates whereas the Universal Design integrates."

- Why should I be concerned?
Safe Investment for future and when I grow old!
- Going to cost me a lot of money?
If included in planning- no extra cost at all!
- Post construction changes- only fractional (less than 1%)
What are the benefits?
- More clientele, committed & devoted employees with disabilities (not floating employees) and more revenue generation.

How one can promote BFE?

- Sensitization & Awareness creation-
There is a great need to create awareness and understand the needs and analyze why we do not come across people with disabilities in our schools, colleges and work environments or in social gatherings. Disability awareness/ simulation exercise for the architects, service providers and stake holders help in creating awareness. Education and training of professionals on this issue plays a significant role in promoting a barrier-free world.
- Access Audits (facilities check) are surveys conducted of existing built environment that needs to be made barrier free or review of architectural plan of a building to be constructed;
- Market and package the concept of Universal Design - "Design for All" Special Designs segregates, while Universal Design integrates!

Barrier-free or accessibility for all the potential users in our society, is one of the important features that needs to be considered when building houses, school, work environment and public utility places. This in itself does not meet the need unless

- Anjee Agarwal (Executive Director) Samarthya

we also create accessible and affordable public transport systems, which connects our house to schools, office, assists us to travel to different places.

Important components of a barrier-free environment:

1. The external environment includes footpaths, curb ramp at walkway, pedestrian crossing, traffic signals, subway and overhead bridge, playgrounds, parks etc.
2. The internal built environments which includes schools, factories, companies, hotels, movie halls, museums, tourist spots, sports complex, public buildings, etc...
3. Barrier-free transport systems. The ability to affordably commute by bus/metro or train like the way most of us do (including equal access to water and air transport).

What is access audit?

Access audits are surveys conducted of existing built environment that needs to be made barrier free or review of architectural plan of a building to be constructed.

One should not take access audit as a fault finding measure but should consider it as an effective tool to bring about possible cost effective changes for access improvement.

The main objectives of access audit are:

- a) Identify obstacles or barriers to disabled persons' movement
- b) Obtain information required for considering solutions on how these obstacles and barriers can be eliminated or remedied.
- c) Document the accessibility of the place surveyed.

Team members shall monitor any changes or action taken by the management or relevant authorities, as well as review action required from time to time.

Use of reports

The reports on survey outcomes are an important source of information for encouraging access improvement. The records may be used for:

1. Comparative purposes in updating information on the changing access

requirements of disabled people from time to time;

2. Reviewing the applicability of existing dimensions as a basis for proposing amendments.

Changes after Access Audit (facilities check)

Pilot project and some research projects undertaken by Samarthyia:

I) Dilli Haat- A Case Study

Samarthyia selected Dilli Haat, a joint venture of Delhi Tourism, Union Tourism Ministry, DC Handlooms & Handicrafts and the Ministry of Textiles as its pilot project. Dilli Haat is spread out over a six-acre site, set amidst idyllic environs that attempt to mimic the rural ambience of a traditional Indian little "Haat" or a weekly village market. It was conceived to be a multi-purpose, cultural complex where artisans from all over the country could come to display and sell unique and ethnic products.

It has high visibility value and ample scope of expansion, replicability and sustainability. On the basis of ticket sales for three months it was found that 180,000 domestic as well as foreign tourists visit Dilli Haat every month. Making Dilli Haat accessible to all would mean spreading the message to other parts of the country.

An access audit in "coordination" with the architect of Dilli Haat was conducted in January 2001. The audit team examined the existing architectural plan of the complex, identified the problem areas and suggested possible solutions.

Samarthyia extended its "cooperation" to the architect and Delhi Tourism by providing standards, guidelines and accessible design layouts. The partnership between Delhi Tourism and Samarthyia resulted in "Barrier Free Dilli Haat" The changes include: leveling of front plaza flooring, demarcated pathway, lowering of ticket counter, merging of level differences and unisex accessible toilet. Around 27 small and big ramps with handrails provide access to Dilli Haat office, exhibition halls, stalls, STD/ISD booth, drinking water facility, and approach to toilets and eatable stalls. The first public unisex accessible toilet as per international specifications was also constructed.

Dilli Haat is the first barrier-free tourist spot in the country and has resulted in increased sensitivity and awareness.

Cooperation and co-ordination between Samarthyia and Delhi Tourism and Transport Development Corporation (DT&TDC) culminated in a commitment from DTTDC that all future projects of Delhi Government will be barrier free including upcoming Dilli Haats and subways! 'Garden of Five Senses', another project of DTTDC, is accessible to a great extent.

Dilli Haat received the National Award for Promotion of Barrier Free Environment for Disabled Persons from the President of India on 3rd December 2005.

II) Research Project on Promotion of User-friendly Public Transportation Systems Bus & Bus Shelters In India

A mixed team of persons with diverse disabilities, architects and students of Industrial Design of School of Planning and Architect was identified as the audit team. Debriefing of the aims and objectives of the research study was done by the Samarthyia Resource team on the site.

Access Audits of Shivaji Stadium and Central Secretariat terminuses were conducted to get a first hand experience of the barriers. Also various bus shelters of Sarojini Nagar, Chankyapuri, Akbar road, Mayapuri, Kirti Nagar, etc. were visited to study the bus shelters designs of both MCD and NDMC. Video recording of personal experiences of persons using various mobility aids was done on the present situation (from origin to destination including access to bus shelter and bus ride). DTC, Blue line and recently introduced Low Floor Buses (LFB) were included in the video recording and personal interviews of the users.

Concept Plan of Barrier free Bus Shelter: A series of meetings between access audit team of Samarthyia, Government officials and architects were held to review the existing designs of various bus shelters (both NDMC and DTC). Video recording, digital photographs and a power point presentation showing the barriers and hurdles faced by PwDs (during the experiential ride and access audit) from the origin to destination while commuting by bus were shown. On the basis of these presentations, designs of barrier free bus shelters were developed. A number of

concept plans of barrier free bus shelters were prepared and discussions held with the users and architects resulted in a cost effective final design.

As the designs of the barrier free bus shelter were ready, Samarthyia approached DTC to implement the designs as model at Hauz Khas Terminal. Letters with copies of the designs were sent to the Transport Department, Delhi State. A presentation was also made at DTC head quarters in which suggestions of better designs of Low Floor Buses and bus shelters. Minister of Transport invited Samarthyia to make a presentation on the above and approved the design of bus shelter which is going to be constructed as a pilot project in Delhi.

III) In co-ordination with Delhi Metro Rail Corporation (DMRC), an access audit of the sample station was conducted in April. Samarthyia followed the construction work till its completion in November 2002. Follow up of BFE features is on with the DMRC officials for all the upcoming stations. As a result of user's group perspective in the planning and construction stage, Delhi Metro has become a beautiful example of Universal Design in public transportation.

Likewise access audits conducted at various places for example- Indira Gandhi Domestic airport and Nizamuddin Railway Stations, New Delhi; RML Hospital; State Emporium Complex, B.K.S. Marg, Government school, State Bank of India and post office; have incorporated barrier free features.

Conclusion

Access benefits All

Barrier Free Environment is creating and maintaining environments in which people can participate in ways, which are equitable, dignified, maximize independence, conserve energy, are safe and affordable. Accessibility is a prerequisite for PwDs to full participation and to have the benefit of equal opportunities including education, employment and enjoy other social activities.



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Now Welcome Aboard Buses without Barriers

□ Gaurav Vivek Bhatnagar

NEW DELHI: A visually-impaired man about 30 feet from a bus terminal in the Capital strains his ears and starts walking towards a speaker installed at the bus stop which beckons him with a recorded announcement, "Welcome to Hauz Khas bus terminal... ." The man soon finds bright yellow guiding and warning tiles beneath his feet that guide him to the bus shelter which also has a ramp for easy movement.

Then as a bus approaches the stand, the blind man does not have to ask other passengers about its route number, for the vehicle has a speaker on board announcing, "This bus is plying on route 620 and going to Shivaji Stadium... ." With the height of the stand being 38 cm, the man is able to simply walk into the bus and take a reserved seat.

This is not circa 2050 but only mid-February 2006 when the first modern disabled-friendly bus shelter will be completed. Approval for the pilot project was given by Delhi Transport Minister Haroon Yusuf at a presentation this weekend and the Managing Director of Delhi Transport Corporation (DTC), A. Majumdar, immediately sanctioned the funds needed for the project.

The design of the new bus stops -- which will be completely compatible with the recently introduced ultra-low floor buses and also the high capacity bus system -- has been prepared by Samarthyra, National Centre for Promotion of Barrier-Free Environment for Disabled People in association with Sabla Action Aid. An example of user, public and government interface, the project has also witnessed keen involvement of IIT Professors Dinesh Mohan and Geetam Tiwari,



School of Planning and Architecture students Nitin and Sudipto, DTC General Manager V.K. Bhatia and Manager (Civil) Ranga.

"The final design which is being implemented will be a big boon for all visually-impaired and mobility aid users who number around 30 lakhs in the Capital. The new shelters will also make life easier for regular passengers as their height is almost that of the first step of the normal Blueline and DTC buses," says Anjali Aggarwal of Samarthyra, herself a wheelchair user.

According to her, the new bus shelters also have parking spaces for two wheelchairs, direct electric supply from poles to operate the speakers and lights, and a front-open cantilever design in which the shelter is supported by three pillars at the rear so that wheelchair users can also park alongside normal seats at the back and move freely towards the bus.

Sanjeev Sachdev of Samarthyra, who has worked hard on the project, said the

design has been made using inputs from experts based in Japan, Britain and other countries and has then been customised for Indian user needs and weather conditions.

"The new design is worthy of emulation in other cities as well and already Bangalore has shown interest in it," he said, adding that after Hauz Khas in Delhi, Shivaji Stadium would be the next to be taken up. "Already we have sent a letter to NDMC Chairperson Sindhushree Khullar since Shivaji Stadium comes under NDMC jurisdiction. Later other stands on the H-620 bus route will be taken up and then the project will hopefully be expanded to other routes."

At present there are about 5,000 bus stands in Delhi of which only about 2,600 have bus shelters. Going by the interest shown in the project by the Delhi Government, it seems in the days to come travel by bus in Delhi is also all set to become more modern and comfortable for one and all.

(This is a press release)

The Changing Educational Scenario For Children with Deafblindness and Multiple Disabilities in India

□ Akhil S. Paul and Sumitra Mishra
Sense International (India), Ahmedabad

The Present Scenario:

Deafblindness is a condition in which there is a combination of visual and hearing impairments that cause "severe needs in the areas of communication, mobility and accessing information". Children who are called deafblind are educationally isolated because of impairments of sight and hearing require



thoughtful and unique educational approaches in order to ensure they have the opportunity to reach their full potential. For deafblind children and their families, the Salamanca Statement was a breakthrough. It was the first major international declaration to make reference to the specific needs of deafblind children. However, in the experience of Sense International (India) and its partners, Salamanca has had little or no positive affect on the numbers of deafblind children accessing formal educational opportunities, and there is little understanding of how a deafblind child can be supported to flourish within either mainstream or specialist settings. On the contrary, Salamanca Statement has been used as a rationale by governments to reduce both the size and the funding available to the special education sector. The overwhelming majority of deafblind children remain as excluded now, as they did in 1994.

The field of Deafblindness, Multiple Disability or the Multi Sensory Impaired (MSI), in the country is a new and emerging field. One of the highlights of this field has been its professional and cohesive approach. There is a lot of value being added by learning from each other and adding a component of additional disabilities on to their own work at this early stage. Till date, the initiatives taken in the field of MSI has been very needs-based. As a result, the services are much localised to regions, target groups and purposes. This has led to development of many forms of interventions and models in the field in a short span.

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act gave a big boost to the disability sector of the country. By identifying the major disabilities and enumerating identification and services methodology, it attempts to build an infrastructure in the country that will be appropriate and accessible for the disabled population in India. Multiple Disabilities is however not recognised as a separate and unique category of disability within this act, which was passed in 1995. Many professionals and parents of people with multiple disabilities came forward and lobbied with the Government about the needs of such people. These efforts resulted in increased identification and establishment of preliminary services for persons with multiple disabilities, which lead to stronger lobbying for identification of multiple disabilities as a separate group.

However, "The National Trust for Welfare of People with Autism, Cerebral palsy, Mental Retardation and Multiple Disabilities" - recognises Multiple Disability as a separate and

unique category of disability. It supports the needs of Multi disabled persons and their family members by promoting and facilitating many awareness workshops in rural and urban communities; collating and disseminating information on multiple disability; facilitating local organisations in setting up day care and respite care services for children and adults with multiple disabilities. The National Trust came as a big boon for parents of children with multiple disabilities, who have looked at the guardianship need for a long time now. One of the major highlights of the National Trust is its vision for the parents of the children. It believes that parents are the key persons in decisions involving the present and future of their children and therefore this is being promoted through its various Local Level Committees and activities.

Present Schemes and Deafblindness:

We all agree that there should be free education for primary school children and midday meals for school going children from below poverty line families. In true sense there should be - "Education for all". Such schemes have reportedly pushed up the school enrolment ratio. More and more younger children are coming to school - including the girl child. Families having deafblind children in the rural areas often decide on sending their child to the school depending on the availability of the midday meal (which is quite logical). As educational professionals, this is also a tremendous opportunity for us to include the child in the mainstream set ups, help him to learn and be independent.

However often in Village school one sees almost 35 - 45 children in one classroom.

1. "Educational policies (can) take account of individual differences and situations... (since) Owing to the particular communication needs of deaf and deaf/blind persons, their education may be more suitably provided in special schools or special classes and units in mainstream schools".

2. There are no comprehensive statistics relating to the numbers of deafblind people. The most effective identification of deafblind people to-date has been carried out by Bradford City Council in the UK, which identified 90 deafblind people per 100,000 (2003). This hints that, in India, we will have around 500,000 deafblind people.

Such class rooms could be open air with a standing blackboard that has its top layer peeling out. At times this group of 35 - 45 children in a class room will include any one from the age of 6 to 10 years. Probably because there is only one teacher in the village primary school! He is aware that every child can come to school. But he has never heard about having to make changes for teaching a child with disability, let alone a deafblind child!

There is a different perspective in the special schools. Traditional schools for the deaf and schools for the blind often have a small group of students who are deafblind. Such students are then categorised as 'retarded'. If there are about 4 or 5 of them, they may be moved to a special class room for 'slow learners'. Such class rooms will often stop following the school curriculum and start with wooden puzzles, craft activities and chair canning!

It is imperative to state here that the issue therefore is not a decision on whether deafblind should be included in the mainstream school or the special school. The larger question is - when do we identify and include the real support needs of deafblind children in our educational policies. Deafblindness is not recognised as a distinct disability; national education plans for achieving "Education for All" do not make reference to deafblindness; no statistics exist to undertake planning; assessment tools are not available; children and parents themselves are excluded from consultation.

Community Based Rehabilitation programmes address the issue of inclusion in a much understated way in India. Field workers visiting families in the village to 'teach' the deafblind children also signal the message to the community that deafblind child are educable. This also highlights the fact that there could be special provisions to teach them. CBR programmes also ensure that children are identified as early as possible. This makes sure that crucial early development period is not lost.

Promises from the Future:

Special schools need to open their doors:

Special Schools for children with mental retardation, blindness, deafness, orthopaedic impairments, autism and cerebral palsy are probably in the most crucial position to take the momentum of multiple disabilities ahead. It is a fact that the parents of children with multiple disabilities approach these schools/centres for guidance and help. Desperate for some kind of positive feedback about the condition of their child and after a series of medical interventions, family members contact school authorities. The special teachers in these schools are the first point of contact for such parents and



children. It is important for the special teachers to be aware of characteristics of multiple disabilities, its needs and demands. The Special teachers need to develop skills to conduct assessment and develop rehabilitation programmes within the purview of their schools. Often the right information or the right referral for such children has actually been of greater help.

Unfortunately, the reality has been that children with deafblindness /multiple disabilities have been turned down at these special schools as they do not strictly fall within their target group. Sometimes real concerns such as lack of information and expertise, no infrastructure and poor staff-student ration are the excuses. But mostly it is the lack of sensitivity and willingness to work with children who are multiply disabled, which forces such children to return to their cocoon of isolation and desperation.

Need for better utilisation of services:

As mentioned above, this field presently is at a very young stage. Parents, local Non-governmental Organisations (NGOs) and government officials are gradually beginning to look at the presence of deafblind / multiple disabilities as a separate and unique category of disability and are slowly discovering that it is different from mental retardation, visual impairment, hearing impairment and even from Mental Illness. Awareness about identifying such persons with multiple disabilities is beginning to take shape to provide them with the appropriate services. However, many more bold initiatives and actions needs to be taken on this front.

Presently available infrastructure in the country has great potential to take this initiative forward. The Person with Disability Act could identify Deafblind / Multiple Disabilities as a separate and unique category of disability, which would ensure better identification and establishment of services for this target group. The National Trust has the potential of facilitating and establishing services to support multi disabled person and their family members across the life span, including services for very young children to adult hood.

Various National Institutes could become instrumental in spearheading identification process and help set up model services for children and adults with deafblindness. The National Institutes could also be instrumental in developing and disseminating information on multiple disabilities to various target groups.



Strong NGOs operating at state, district and block level have a major role and responsibility in making an impact in the local community. Local NGOs have wider acceptance within their own regions, and thus are better empowered to increase awareness. The NGOs are in a great position to raise sensitivity screen and identify persons with deafblindness. They can interlink with other existing organisations both government and private, in creating local infrastructure to provide services for persons with deafblindness / multiple disability and their family members.

Parent Associations have a major role in bringing about positive changes in this area. They could play a crucial role in influencing the decisions of government and local organisations towards the policies and schemes for people with deafblindness / multiple disabilities.

It will be fully justifiable to list the following as priority areas:

- **Identification:** The need of the hour is to identify deafblind as a separate and unique category of disability in all relevant statutory laws and documents.
- **Incidence and Prevalence:** It is extremely important at this stage to include deafblind as a separate category in different surveys, such as the National Sample Survey Organisation (NSSO).
- **Assessment and evaluation:** For effective assessment, it is necessary to develop a mechanism that could be used across the country (with some regional variations), for identifying persons with deafblindness / multiple disabilities and their needs. Such a system will empower even the grassroots level workers to identify the multi-disabled persons in their respective regions.
- **Human resource development:** As the field is growing, it is most needed and important to identify and involve more and more professionals from the single category disability areas. We also need to look into the areas and ways of offering skill developing

programmes for creating a pool of trained human resources.

- **Social Communication:** The development of appropriate material for social communication is of utmost importance in order to spread awareness about deafblindness and its various implications.
- **Networking:** As more and more people around the country have realised the hazard of 'professional isolation' that generally comes with such low incidence disabilities, now they are coming together. Therefore there is an urgent need to form and sustain continuous networking activities both within the NGOs and with the government sector.
- **Advocacy:** It is important that the community takes responsibility of the people with deafblindness / multiple disabilities in their own community programmes. And this could be done by advocating for the rights of this target group and their family members at the local community levels as well as in a regional and national level.
- **Involvement of parents:** Children with deafblindness / multiple disabilities, their parents and other family members are the primary stakeholders of the services established around the country. It is very important that they be involved in the decisions making process which involves for their child.

Conclusion

The needs-based initiatives of deafblind field have resulted into many services, which are much localised to regions, target groups and purposes, leading to development of different forms of strategies, interventions and models. These models are now forcing us to look beyond the established services to find out the ways in which these can be strengthened and new endeavours could be incorporated within the field.

Currently there are several initiatives undertaken by the many National level government and non-government



organisations. There has been regular Orientation Workshops on deafblindness / multiple disabilities for teachers working with single disability children such as visual impairment, hearing impairment and mental retardation. Such workshops are aimed at equipping teachers to identify and work with children having multiple disabilities.

More significantly, all the Diploma courses on single category disabilities now include a specific paper on multiple disabilities. At the end of the course the special teachers would be able to identify additional disabilities present in a child and to plan appropriate programmes. The possibility for developing a distance-learning course on multiple disabilities for teachers trained and working with single category disability is also being explored.

The Authors are Director and Deputy Director (Programmes) of Sense International (India), a young organisation that was set up in 1997 to support the development of sustainable services for deafblind children throughout the country. Sense International (India) is the only national NGO that is currently working for persons with deafblindness and also includes persons with multiple disabilities within its activities. As on today, Sense International (India) has been successful in starting services in 17 states of India. In a country, where till 1997, there was only one service, it is commendable that there are now 33 services but with a country sized as India, merely 25 services are not adequate. Sense International (India) wants to reach out to many other states where there are no services at the moment. It has a vision of "establishing at least one quality service in each state of India by the year 2010".

Poorest Areas Civil Society (PACS) Programme

A Partnership Initiative against Poverty

The Poorest Areas Civil Society (PACS) Programme is probably the single largest anti-poverty programme being implemented in India by a network of Civil Society Organisation (CSOs).

Supported by the UK Government's Department for International Development (DFID) and Managed by Development Alternative and PricewaterhouseCoopers (P) Ltd., the PACS Programme focuses on the 108 poorest districts of India. Over 80% of India's poorest districts are located in the states of Bihar, Chhattisgarh, Jharkhand, Madhya Pradesh, Maharashtra and Uttar Pradesh. These are the states covered by the Programme.

A seven-year programme, PACS has completed three year of implementation. The programme already has a network of 350 CSOs in 78 districts, covering over 12,000 villages in these six states.

Objective: Empowering the Poor

PACS aims to empower the poor so that they can exercise their rights and demand their entitlements. The Programme aims to achieve this by strengthening the capacity of CSOs working for the poor in the target districts.

For more information visit us at: www.empowerpoor.org



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