

ADDRESS BY MANEKA GANDHI*

I just wanted to say that Prof. Verma has made an interesting point about that we do not know the number of disabled people in India. It is very strange, and it impinges on this entire debate. That is why it is necessary to explain the steps taken by me on this issue. I have for the last two years been trying to get the census people to do a census because I think it is very important. Finally the Registrar General agreed to do the census. However, I wish to add that when we did a census in 1981, not a single person who is disabled told us that he was disabled, nor did their families admit it. That is why we do not have the figures. If we do not co-operate and repeat the same attitude in this 2001 Census, a correct picture of the number of disabled persons cannot be known. We cannot know the exact number of physically, mentally or visually disabled persons. In view of this we had asked a sample survey from the National Sample Survey Organisation (NSSO) to see whether we are any closer to being able to identify them. Thus the attitude is not just the people towards the disabled, it is the disabled towards themselves.

In the last decade and a half there has been a growing awareness and a significant landmark in the disability sector both at the national and international levels. Following the period of 1993 to 2002, which is proclaimed by the General Assembly as the 'UN Decade for Disabled Persons', a global movement has emerged which recognises the importance of integration of people with disabilities into society. The emerging international trends as well as national issues relating to the disabled population have had a direct impact on the thinking of policy makers, professionals, persons with disabilities and non-governmental organisations working in the country. As a result of shift in policy in the mid-90's, today the issues relating to the disabled are no longer mere welfare measures but have grown into fundamental human rights issues, a demand for full participation, equal opportunity and protection of rights. The shift in emphasis led to the realisation of the need for enacting legislation to ensure empowerment.

The legal commitment that took place, took shape with the enactment of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act in 1995. This is a comprehensive piece of legislation, which, *inter alia*, treats rehabilitation as a right and aims at the elimination of discrimination and creation of a society which provides

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opportunities for the development of people. While it is a good Act, unfortunately it has not been used much and specially the three percent reservation of jobs in the government and public sectors is not used at all in spite of several judgements, directives and constant letters. This part of the Act, while it is a minor part, I say this because even if we were to employ three percent it will lead to a couple of hundred people only but even then this piece is often referred to by concerned people as the main part of the Act because it is not followed at all.

The 1995 Act provides for both preventive and promotional aspects of rehabilitation like education, employment and vocational training, reservations, research and manpower development and also creation of a barrier-free environment, which is another thing that doesn't work at all. Rehabilitation of persons with disabilities, employment, unemployment allowance for the disabled which again is hundred rupees a month in some states, and seventy five in others, provided you make two hundred trips to the local doctors and the District Magistrates to show how disabled you are. And also it has so many provisos, you have to be disabled with both legs and both arms. Your mental retardation level has to be judged by people who do not have the instruments to judge it or the capabilities or even have no interest. Special insurance schemes for the disabled employees and establishment of homes for persons with severe disability are also totally lacking in the private sector. This Act has been enforced, if you can call it enforced with effect from February 7, 1996. While the Persons with Disabilities Act ensures equal opportunity and full protection and participation of the disabled, it does not provide for economic emancipation of the mentally retarded persons or persons suffering from autisms, cerebral paralysis, multiple disabilities. This is a lacuna, which the honourable Justice S.P. Bharucha has pointed out in his welcome address. Since they represent the most marginalized of the disabled they are not in a position to articulate their needs.

A legislation for setting up a national trust for persons with autism, cerebral palsy, mental retardation, multiple disabilities was introduced and passed by Parliament in December, 1999. The Government is in the process of setting up this trust, which doesn't just provide for children with disabilities but for their parents, family and guardians, for making available manpower to look after such children and to provide other facilities for them. The objectives of the trust are tailor-made for these groups and include provisions like strengthening facilities to support people within their own families, within society and, as I said, extend support to parents and voluntary organisations, during a period of crisis, and promote measures for their care and protection after the death of their parents or guardians. Thus, the functions of the Trust include setting up of residential hostels and homes, foster care, day services, counselling use. A provision for appointment of guardians and acceptance of the

bequest from parents of such disabled is also made.

The priority before the government in the sector of disability and rehabilitation is at present to reach out to as many disabled people as possible throughout the country to provide necessary services. The Rehabilitation Council of India (RCI) was set up under the Rehabilitation Council of India Act, 1992 for standardisation of training courses at different levels, recognition of institutions in the area of rehabilitation and maintenance of a Central register for professionals possessing recognised qualifications in the area of rehabilitation. The RCI has also taken up new programmes for training of personnel in disability rehabilitation. Last year alone, they have trained over twenty five thousand people. The registrations are now much quicker; the inspections are almost instantaneous, so that we can have a network of services. The government has been sensitive or rather more sensitive to the aspirations and needs of the disabled. We have conducted a review of both the Persons with Disabilities Act and the Rehabilitation Council of India Act with the objective to rationalise and make the legislations more comprehensive which would also be in consonance with each other, and assist in implementation of the provisions of the Act. Amendments have been proposed to both the Acts, which are under consideration of the government. It is envisaged that with these amendments, a further step will be taken to ensure the rights and opportunities of the disabled.

At the ground level, not just the Act, we have also come up with new schemes to provide rehabilitation services to the disabled at their doorsteps. We propose to set up six regional resource centres, which will act as extended outreach centres for the existing National Institute of Disability. Four centres for the rehabilitation of the spinally injured, under the national programme of the rehabilitation of persons with disabilities based on the community based rehabilitation approach, a four-tier system for rehabilitation services at the state, district, block and gram *panchayat* levels is proposed to be set up, for which hundred percent funding is being given by us to the states. In addition to these schemes, a hundred and six districts have been identified all over the country which will be adopted by the national institutes and the Artificial Limb Manufacturing Company of India (ALIMCO), as well as eleven district rehabilitation centres under the Ministry of Social Justice and Empowerment. The aim is to set up composite fitment centres for disabled people at the district level. Until now what has happened is we have worked in two ways: either the person is lucky enough or has enough money to come to Delhi or Bombay, or to Hyderabad, to fit himself up with the limbs, or he has to wait till we set-up a camp. Now these camps are set-up once in every week for the first time since independence. However, I go to most of the camps and I am personally dissatisfied with the camps because when we go to a place like Vaishali in Bihar, and we give the limbs for instance for

the legs to a six year old, while the next year the child is going to turn seven and that limb is no longer going to fit, we have found that in these camps a lot of limbs are just thrown away or the child keeps them out of desperation, since she knows that she is not going to get another one and then this spine becomes dislocated or injured making her problems much worse. This year we have decided to set up a hundred and six centres which means one centre services six districts, where there are permanent fitments. For the visually disabled also, we used to have camps. Now we have a camp every week, but again it is not just confined to cataract, which is only one of the problems and which is the one that people focus on most. Sometimes when you are poor the only thing that is wrong is that you need a pair of glasses, you do not have the money for them, and nobody has told you what your number is, so you are as blind as if you were technically blind. So we check your eyesight, we give you glasses. Some times you have tumours and you don't realise, so we bring you back, you are treated in a hospital if your blindness is related to a tumour. So these are some of the things that are going to be in these hundred and six centres, which will be set-up this year. And this scheme is being executed in direct partnership with the district authorities with support from the state government.

As a part of the attempt to reach to a large number of disabled persons, four auxiliary production centres will be set up by ALIMCO, so that quality aids and appliances are available to the disabled people easily at a reasonable cost. I would like to mention here that when I came to Ministry, ALIMCO was a severe loss-making unit, which had absolutely no importance in this scheme of things. However, today ALIMCO is not only making a very healthy profit, it has almost tripled its production, and is now setting up four auxiliary units so that we can have enough aids to give to people. As a result of the new thrust towards decentralised availability of services, it is hoped that in the new millennium we have services as envisaged in the PWD Act and will be available all over the country through an equitable geographical distribution and also by local capacity building and empowerment of target groups. It is within this context, the legal professionals become important since we expect convergence with the existing services in the areas like health, family welfare, women and child development, rural development. So it is important that our legal professionals also become sensitive to the issues at hand in regard to the legislative rights of the disabled.

I hope that the discussions being initiated today will create an environment for providing effective guarantees to the disabled and perhaps penalising (if such a thing is possible) people who do not take the Persons with Disabilities Act seriously especially perhaps in government and public sector. In the domain of social legislation, effective implementation is the crucial issue. So far the intentions of the government for the

protection and welfare of persons with disabilities enshrined in the various Acts is concerned, all implementing agencies in the government as well as society in general have to work together to translate the benefits into tangible reality to demolish the barriers not only physical but social and mental, which impede the development of our disabled citizens. The role of the legal system as well as bodies such as the National Human Rights Commission are of utmost importance in our endeavour to ensure equal rights for people with disabilities we must all move forward together.