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Disability in India-Needs Urgent Attention

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Abstract

Around 400 million disabled persons live in the developing world. Most often they are the poorest. Poverty is the most important cause of disability. Every year millions of people go below the poverty line. This makes them more vulnerable to disability. The disabled are deprived of all opportunities for social and economic development. The basic facilities like health, education and employment are denied to them. The State infrastructure is grossly inadequate and ill functioning where disabled are concerned. Millions are in the verge of collapsing due to severe disabilities. People with physical disabilities at least get noticed, but the others with mental illness are just written off. Along with the physical problems they also bear the brunt of social ostracism and stigma. Disabled are also not a homogenous group. There are different types of disabilities, with different requirements. Each one's problems, needs and help required are different from the other. In spite of several international and national pronouncements the rights of the disabled has remained on paper. Given the magnitude of the problem it is important that disabled persons receive political attention. It is important to note that all the targets and policies of achieving social and economy equality will not be possible to meet if the concerns of the disabled are not addressed. There is need for policy level changes backed by adequate budgetary allocation.

Key Words: Attitudes, Disability, Opportunities, Preventable, Stigma.

The Issues: The 1991 round of the Sample Survey conducted by the National Sample Survey Organization estimated that people with visual, communication and locomotors disabilities number at least 14.56 million, or 1.9% of the total population of India. This figure covers only people who are “profoundly disabled”, and does not include those with moderate to mild disabilities, who could, with a little effort, be integrated into efforts for rural development. Also not included in this figure are people with mental disabilities and those affected by leprosy and deteriorating neuro-muscular conditions (e.g., muscular dystrophy, motor neurone disease, Parkinson’s disease and senile dementia). A separate Sample Survey of Mental Retardation estimated that 3% of all children aged 0 to 14 are developmentally delayed. However, this figure once again excluded children with learning disabilities (e.g. dyslexia), or those referred to as slow learners. Again, about 5% to 10% of the general population of India is estimated to suffer from mental disorders of varying types and degrees of severity. Village level survey in different parts of the country indicates that 4%- 10% of the population are persons with disabilities. Available figures and disability statistics should be interpreted with a degree of caution. Many families are reluctant to report disability, particularly in view of the prevailing negative attitudes to disabled persons in most communities. In some instances, the data collectors, or even the informants themselves, may simply not have the knowledge and experience required to recognize that a person is disabled. According to the NSSO

58th round survey in 2002 there are 18.49 million people in India who are disabled. This number has increased from 13.67 million in 1981 to 16.36 million in 1991. Out of the 18.49 million disabled people, 10.89 million males and 7.56 million are females, which constitutes of around 59 per cent males and 49 per cent males and females respectively. These are the people who are suffering from some form of disability. The World Health Organization defines disability as any restriction or lack (resulting from an impairment) of ability to perform in a manner or within the range considered normal for a human being.

Understanding Disability: Types and Forms: Disability is difficult to define since it varies in type, form and intensity. Understanding disability will require understanding these differences. According to the World Health Organization “Disability is any restriction or lack (resulting from an impairment) of ability to perform in a manner or within the range considered normal for a human being”. Persons with Disability Act 1995 defined as a person suffering from not less than forty per cent of any disability as certified by a medical authority. The disabilities identified are, blindness, low vision, cerebral palsy, leprosy, leprosy cured, hearing impairment, locomotors disability, mental illness and mental retardation as well as multiple disabilities.² The NSSO considered disability as “Any restriction or lack of abilities to perform an activity in the manner or within the range considered normal for human being”. It excludes illness /injury of recent origin (morbidity) resulting into temporary loss of ability to see, hear, speak or move.

Types of Disability:

Locomotors Disability: Locomotors disability is defined as the person’s inability to execute distinctive activities associated with moving both himself and the objects, from place to place and such in ability resulting from affliction of musculoskeletal and/ or nervous system. Some common conditions giving raise to locomotors disability could be poliomyelitis, cerebral palsy, autism, amputation, injuries of spine, head, soft tissues, fractures, muscular dystrophies etc.

Visual Disability: Visual Disability or Blindness refers to a person’s inability to see either fully or partially. A visually disabled person is known to be suffering from visual impairment. Low Vision or Poor Eye Sight: A person with low vision or poor eyesight is one who continues to have the problem even after going through medically approved corrective measures. This person with poor eyesight is still in a position to continue his tasks with appropriate assisted devices.

Mental Illness: Mental illness can include both mental ill health and retardation. Mental retardation is defined as a state of arrested or incomplete development of the mind, which is specially characterized by impairment of skills manifested during the development period which contribute to the overall level of intelligence, i.e., cognitive language, motor and social abilities. Mental ill health constitutes of schizophrenia, anxiety disorder and depressive disorder or any other problem, which is caused due to series of chemical changes in the brain. **Speech and Hearing Disability:** Speech and Hearing Disability is referred to a condition wherein the person is incapable of speaking and hearing any sound.

Learning Disability: It is a disorder, which affects the basic psychological processes of understanding or using written or spoken language. This disorder affects development of language, speech, and reading and associated communication skills needed for social interaction. Conditions such as brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia are examples of learning disabilities.

Multiple Disabilities: A combination of two or more disabilities as defined in clause (i) of section 2 of the Person with disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act

1995 namely Blindness/low vision Speech and Hearing impairment Loco motor disability including leprosy cured Mental retardation and Mental illness. Given the type and nature of their problem the disabled are encountered with different types of problems. Some problems are common others are disability specific.

Most disabilities are easily preventable: In India, as in other developing countries, the major causes of disability are malnutrition, communicable diseases, infections in early childhood and accidents at home and at work. Nutritional deficiencies, inadequate sanitation, insufficient or inaccessible health care services, accidents and injuries from poorly-designed equipment and implements, and practices like consanguineous marriages, have all contributed to a high prevalence of disabilities. Immunization programmes have not yet achieved 100% coverage, due partly to inadequate infrastructure, logistical problems and difficulties in maintaining the cold chain, and partly to the lack of public education on the subject. It has been estimated that an effective primary health programme can prevent about half of all disabilities. Early detection of impairment, combined with early and effective curative care can make a significant impact in minimizing or compensating for impairment and its consequence.

The rural poor are most vulnerable to disability: About 80% of people with disabilities in India are in the rural areas. The rural poor are particularly at risk of those disabilities which are associated with malnutrition, poor conditions of environmental sanitation and communicable diseases. Accidents arising from negligence, ignorance and lack of safety measures at work and the community are also major causes of disabilities. Persons with disabilities are a heterogeneous group composed of those born with a disability, those who acquire a disability following micro nutritional deficiencies and/or disease, as well as those who become disabled as a result of accidents or the trauma of life events. They include children and young people, adults and elderly persons. Their disabilities may be extensive or moderate and they may have a single disability or be disabled in multiple ways. However, whatever their particular type or degree of disability, they have the same basic needs as other members of the age, gender, economic and socio-cultural group to which they belong. People with disabilities who are members of poor rural families are therefore marginalized and disadvantaged by a variety of factors – lack of access to productive resources, and to the opportunities, information and skills which enable participation in social, economic and political processes. In addition to these, people with disabilities are further disadvantaged and handicapped when they encounter social, cultural, physical and economic barriers which severely limit the opportunities for them to participate in the life of their communities on equal terms and to an equal extent as non-disabled persons. Because of the prevailing lack of understanding of and concern for their participation, rural persons with disabilities, particularly those who are members of poor families, are most vulnerable to economic and social handicaps. Equalization of opportunities is the process whereby the structures and systems of society are made accessible to people with disabilities. This includes all aspects of the physical and cultural environment, services, facilities and development programmes which are designed for use by the public or which are the entitlement of every citizen, including those who are poor and have a disability. However, poor rural people with disabilities and their families have little or no access to the opportunities, information, technologies and programmes that are available within India for rehabilitation or participation in the development process. Parents and caregivers in extremely poor families, whose only source of income is daily wage labour, are hard pressed for time and other resources needed to provide appropriate care to persons with disabilities, or to take advantage of existing rural development

programmes and rehabilitation services, even if the necessary information and skills were to be made available to them.

Initiatives have remained urban-based and welfare-oriented: Most efforts in the field of disability have so far, been made by health professionals and charitable organizations. While the majority of Indians with disabilities live in rural areas, available services are limited to urban centres. It is estimated that only 2% to 3% of person in need of rehabilitation, have access to these services. The Ministry of Welfare is the nodal Ministry for disability matters. While this has, on the one hand, served the need for focused policies and initiatives to promote the interests of this highly marginalized social group, it has, on the other hand, also reinforced a conventional tendency for other Ministries to view disability-related issues as mere welfare matters which have no bearing on their respective mandates and schemes. Consequently, people with disabilities have largely been bypassed as participants in mainstream programmes. Programmes designed specifically for the rural poor are no exception to this pattern. In the absence of critical linkages with other development sectors, little headway has been made in equalization of opportunities for people with disabilities. While there has certainly been concern for rural people with disabilities, it has been based on the perception that they are mainly in need of relief and alleviation of suffering. Initiatives based on such an approach have trapped them in situations of dependency and helplessness. There has been a predominance of action for medical intervention without adequate respect for the dignity, rights and potentials of persons with disabilities. Medical rehabilitation is important, but it is seldom realized that it is a goal-oriented and time-limited process. Thus, rehabilitation is not an end in itself but is a means of enabling persons with disabilities to reach an optimum level of functioning, which allows them to contribute as active members of their communities. Putting the label of 'rehabilitation' on all action concerning disabled persons can obstruct fulfillment of their potential for self determination and participation.

Attitudes are a major barrier to equalization of opportunities: While lack of services and lack of knowledge and technology are serious constraints, perhaps the greatest obstacle to full participation and equality is the prevalence of negative attitudes on the part of non-disabled persons in the family and the community, as well as in the voluntary sector, the development machinery and the administration. While planning and designing programmes and interventions, the general tendency is to view persons with disabilities as members of an insignificant minority who merit attention only as medical cases or objects of charity. Their humanity, aspirations and potentials, and the fact that, as citizens of India, they have the same entitlements as non-disabled citizens, are usually not recognized. At the individual level, discrimination on the ground of disability is a common experience in the daily life of a person with disability the expression of this discrimination may range from receiving a smaller share of resources within the family, to the difficulties encountered in gaining access to programmes of services specifically intended for the rural poor. Marginalization stemming from a rigid and hierarchical caste structure compounds these difficulties. Negative attitudes are closely linked with widespread ignorance of the situations, problems and potentials of persons with disability in society. At the same time, despite the encouraging development of many small organizations (sanghams) of disabled persons in South India, self-advocacy by persons with disability is still very weak in rural areas. One outcome of all these factors is the non-participation of this group in mainstream development programmes, including those for rural poverty alleviation. There has, as yet, been no review of mainstream development programmes in India to examine their impact on people with disabilities and the possibilities of convergence with disability-focused schemes.

Future Directives for Planning and Development of Programmes for Disabled:

- Rural people with disabilities are members of their communities and citizens of India. They are entitled to participate in the process of rural development, both as partners in processes of decision-making and planning, and as beneficiaries of programmes meant for the rural poor.
- Specific measures are needed to enable people with disabilities to transcend the attitudinal and physical barriers to their participation in rural development programmes and projects. These measures should focus on social mobilization (changing of attitudes among non-disabled persons and building of confidence and self-esteem among people with disabilities), as well as on elimination of physical and logistical barriers to their participation.
- The process of ensuring that rural people with disabilities avail their rights and entitlements is the joint responsibility of all persons concerned with rural development.
- The rich experience of the voluntary and non-government development sector in India in primary rehabilitation, social mobilization and organization of community action for rural development can be tapped to facilitate the participation of rural people with disabilities, in development programmes.
- As basic rehabilitation services, assistive devices and access to the rural built environment are prerequisites for participation in development programmes, these should be considered a basic entitlement of poor rural people with disabilities.
- For families and communities below the poverty line, basic rehabilitation services need to be delivered to where they live, in forms and at times convenient to them. These basic rehabilitation services include early identification and diagnosis, regular health check-ups and treatment, assessment of physical, sensory and intellectual levels of functioning, early intervention, referral and integration in existing programmes.
- Community-based rehabilitation (CBR) is, in its broadest sense, social action to mobilize community and other resources to equalize opportunities for persons with disabilities to participate in education, skill development, decision-making, housing, transport and development schemes. In all CBR related activities, the right of people with disabilities to participate in the planning and delivery services must be respected.

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