

Challenges in Rehabilitation and Issues in Disability Services

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Abstract

Disability is an important public health problem especially in developing country like India. The problem will increase in future because of increase in trends of non-communicable diseases and change in age structure with and increase in life expectancy.

Introduction

Any restriction or lack of ability to perform an activity in a manner or within the range considered normal for the human beings, resulting from impairment is termed as disability. The types of disability include loco-motor, hearing, speech, visual and mental disability. WHO in 2000 which has been used in the Multi-Country Survey Study during 2000 and 2001 and the World Health Survey Program in 2002 and 2003 to measure health status of the general population in 71 countries. The ICF considers that every human being can experience some degree of disability and it is a continuous process from attainable level of health. With this background, the paper discusses various issues and challenges related to disability and rehabilitation services in India.

Review of Literature

Recent data was collected from Medline and various other sources. Information gathered was summarized for Indian context and analyzed for discrepancies. Information was depicted under categories of problem burden of disability and its socio-demographic characteristics, determinants, service delivery under community-based rehabilitation, challenges ahead and recommendations to address the problem in the country.

Problem Burden

Globally, around 785-795 million persons aged 15 years and older are living with disability based on 2010 population estimates. Of these, the World Health Survey estimates that 110 million people (2.2%) have very significant difficulties in functioning while the Global Burden of Disease Survey estimates 190 million have (3.8%) have severe disability. Including children, over a billion people (about 15% of the world's population) were estimated to be living with disability.

In contrast, the National Sample Survey Organization (NSSO) report and Census data of 2001 stated that its prevalence was as low as 2% in India. A recent community-based study in India found the prevalence of all types of disability as 6.3% out of which mental disability was found to be the most common type

of disability (36.7%). A study in Chandigarh reported that 87.5% of elderly people had minimal to severe disabilities. Another study in Dehradun showed that visual disability was the most common (74.1%) among the geriatric age group. A community-based study conducted in Rajasthan among children below 14 years found that 7% of them had at least one or other form of disability. Another study in Gorakhpur found that in children below the age of 6 years the disability rate was 7638 per lakh population. In India, NSSO reported that a total of 1,40,85,000, and 44,06,000 people are disabled in rural and urban areas, respectively. Overall, 1846 and 1499 per lakh population had any type of disability during the survey in rural and urban areas respectively. With respect to gender distribution, some studies showed proportionately more disability among males, while some other studies more among females. Lack of education among disabled is an important barrier for effective delivery of services and 54.7% of disabled belonged to illiterate category according to NSSO 2002 survey findings. The differences observed in various studies are mainly due to difference in methodology adopted, conceptual framework, the scope and coverage of surveys undertaken, operational definitions used for various types of disabilities along with difference socio-cultural, and risk factors prevailing in that area.

Determinants

The global burden of disease study (GBD) provides a standardized approach for epidemiological assessment and uses a standard unit called as the disability adjusted life year (DALY), to aid international comparison. DALYs express years of life lost to premature death and years lived with disability (YLD), adjusted for the severity of disability. One DALY is one lost year of healthy life. Only about one-quarter of the total disability burden at global level is due to Group I conditions that includes communicable, maternal and perinatal factors reported mainly from South Saharan Africa and India. In terms of numbers or years

lived with a disability, there is more non-communicable disability in India than in the Established Market Economies. As countries pass through the health transition, the distribution of YLD shifts away from Group I conditions. In 1998, an estimated 43% of all DALYs globally were attributable to non communicable diseases and in low and middle income countries, the figure was 39%. In India, although both communicable and non-communicable diseases are prevalent in urban and rural areas, there is paucity of data on these factors causing various types of disability and to assess its rural-urban differences. But, the deaths from non-communicable causes are projected to almost double from about 4.5 million in 1998 to about 8 million a year in 2020.

Community-Based Rehabilitation

CBR is a comprehensive approach at primary health care level used for situations where resources for rehabilitation are available in the community. In addition to transfer of knowledge related to skill development in various types of rehabilitation methods, community also will be involved in planning, decision making, and evaluation of the program with multi-sectoral coordination. Besides, referral system will be there for those disabled who cannot be managed at community level and referred to district, provincial, and national levels.

There are many measures initiated by Ministry of Social Justice and Empowerment and Health and Family Welfare in India.

1. District Rehabilitation Center (DRC) Project started in 1985.

2. Four Regional Rehabilitation Training Centers (RRTC) have been functioning under the DRCs scheme at Mumbai, Chennai, Cuttack, and Lucknow since 1985 for the training of village level functionaries and DRCs professionals, orientation and training of State Government officials, research in service delivery, and low cost aids. Apart from developing training material and manuals for actual field use, RRTCs also produce material for creating community awareness through the medium of folders, posters, audio-visuals, films, and traditional forms.
3. National Information Center on Disability and Rehabilitation
4. National council for Handicapped Welfare
5. National Level Institutes—NIMH, NIIH, NIVH, NIOH, IPH.
6. A new scheme District Disability Rehabilitation Centre for persons with disabilities launched by the Hon'ble Minister of Social Justice and Empowerment, Government of India in Jan/Feb. 2000 is a step towards providing rehabilitation services and implementation of Persons with Disability Act. 1995. The Government has decided to set up District Disability Rehabilitation Centres (DDRCs) in a phased manner. Presently, 199 DDRCs have been sanctioned and 100 new DDRCs are to be set up during the remaining two years of the 11th Plan. The DDRCs were established with the objective of providing comprehensive services to the persons with disabilities at the grass root level. The services include awareness generation, survey, identification and early intervention, counseling, assessment of need for assistive devices, provision/fitment of assistive devices, and their follow up/repair, therapeutic services like Physiotherapy, Occupational Therapy and Speech Therapy, referral and arrangement for surgical correction through Government and Charitable Institutions, facilitation of issue of Disability Certificates and bus passes, sanction of bank loans, and promotion of barrier-free environment.
7. The National Policy for Persons with Disability 2005 is the recent development and welcome step by the Government of India.

Service Delivery System for Community-Based Rehabilitation

1. At district or provincial level which caters around 20% of the disabled requires

general physicians, intermediate level supervisors, orthopedic technicians, resource teachers and vocational trainers. National level professionals will be involved in delivery of complex rehabilitation services as well as training and supervision of personnel for district, provincial, and national levels

2. Efforts

Challenges

- Mystification of knowledge
- Resources
- Lack of intersectoral coordination
- Lack of coordination between Government and others.

Recommendations

1. Advocacy for mainstreaming the systems and services. It requires commitment across all sectors and built into new and existing legislation, standards, policies, strategies, and plans.
2. Invest in specific programs and services for people with disabilities. In addition to mainstream services, some people with disabilities may require access to specific measures, support services, or

training. In this process, involvement of persons with disability is of paramount importance as they give insight into their problems and suggest possible solution.

3. Capacity building of health care providers and program managers. Human resource capacity can be improved through effective education, training, and recruitment. A review of the knowledge and competencies of staff in relevant areas can provide a starting point for developing appropriate measures to improve them. Manpower generation by promoting new courses and initiating degree and diploma courses like Physical Medicine and Rehabilitation will address the problem of shortage of manpower in long run.
4. Focus on educating disabled children as close to the main stream as possible.
5. Increase public awareness and understanding of disability. Governments, voluntary organizations, and professional associations should consider running social marketing campaigns that change attitudes on stigmatized issues such as HIV, mental illness, and leprosy. Involving the media is vital to the success of these campaigns and to ensuring the dissemination of positive stories about persons with disabilities and their families.
6. Generating representative community-based data will help to plan and execute appropriate measures to address the problems of persons living with disability.
7. Strengthen and support research on disability.