On Question of Feasibility of Community Based Rehabilitation (CBR) for the Disabled in SAARC Nations: A Journey Away from the Normative Plinth

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Abstract

The incidence of disability is fast increasing in the industrialized world that we live in. The WHO (2010) study indicates that at least 10% of the population of a developing nation suffers from one kind of disability or another. However, the statistics generated from the Censuses of all SAARC nations (barring Sri Lanka) report the percentage of disabled to the total population at a bare minimum, exposing the casualness in the measuring technique. A study on the funds allocation towards disability rehabilitation in India reflects that the flow has rarely been need-based. Grossly violating the basic principles of the Community Based Rehabilitation plinth that promises rehabilitation for the disabled at their places of residence, the flow of funds has been opportunity based. Borrowing from the famous Poverty and Famines: An Essay on Entitlement and Deprivation (1981), we can argue that the rehabilitation environment has not been affected by paucity of funds, but from inequalities built into mechanisms for distributing it like bottlenecks in supply chain, asymmetric information, and mismatched demand supply. As these asymmetries characterize underdeveloped countries, we can safely assume that the lacuna in disability rehabilitation exists in the other lower-middle income countries of the SAARC region as well.

Introduction

The incidence of disability is increasing fast in the industrialized world order that we live in today. With around 500 million people in this world being disabled (UN documents, 2007), the need to generate effective measures in rehabilitation for the people with disability (PWD) has become a growing concern for planners [1].

The rehabilitation environment in developing nations needs to be specially analysed because generally the disabled here are extremely poor. This, along with dearth of resources, insufficient trained personnel and weak linkage effects, has tended to compound the problem. The Development Action Report, World Health Organization action plan 2006-2011 (key activity No.6) reports even after 25 years of the adoption of Community Based Rehabilitation (CBR) only five to 15 per cent of the PWD has been able to access assistive device/technology in developing countries [2].

It would also be worthwhile to note at this juncture that medical care facilities in developing countries are concentrated in urban areas where only 25 per cent of the population reside, reflecting the woefully inequitable provisions of health care services [3]. The position of the disabled in India has also been contrary to the UN Enable Convention on the Rights of People with Disability stand that targets mainstreaming of PWD and promotes availability of assistive technologies, giving priority to technologies at an affordable cost.

Reporting from a developing nation background, we, in this paper, aim to look into the disability statistics of India with respect to its SAARC neighbours. In the second section we propose to do an in-depth study on the rehabilitation environment handed out to the locomotor disabled from a quantitative point of view with special focus on the causes of non-receiptencies of aids and appliances in India.

On the basis of (i) the above-mentioned DAR, WHO Action Plan Report, (ii) poor rehabilitation performance in India and (iii) the fact that rehabilitation for PWD has dwelled on the structure of Community-Based Rehabilitation (CBR) (WHO, 1970), we question the feasibility of the system in the third section [4].

Disability Statistics of SAARC Nations

The WHO, 2000 study on disability in developing nations states that even by modest estimates 10% of the population suffer from one form of disability or the other. An UN study of 2001 puts the figure at 20%. Table 1 reports the total population, total number of disabled and the per cent of disabled in each disability category citing the last available Census figures for Pakistan, Bangladesh, Nepal, Bhutan, Maldives, Sri Lanka and Afghanistan, seven countries which form a cartel of South Asian Association for Regional Cooperation (SAARC) along with India.

The table reveals:

1) Among the total disabled population, number of people with locomotor disability is highest for India, Bangladesh, Afghanistan, Maldives and Nepal.

2) There has been a sharp under-enumeration in disability figures across all SAARC nations, except for Sri Lanka.

However, enumerating higher disability figures should not be the purpose of the enumerator, but absence of comprehensive and reliable data on disability has definitely been a severe deterrent while designing policy for the disabled. The uses of terms for identifying different
categories of disability as has been used in the Census reports of countries reflect severe violation of human rights of an individual. As the purpose of development is to enlarge people's choices [5], under-enumeration of the disabled has led to a social exclusion.

| Name of the country | Total population | Total disabled | Disabled as a percentage of total | Seeing | Speech | Hearing | Locomotor | Mental | More than one disability | Others |
|---------------------|------------------|----------------|-----------------------------------|--------|--------|---------|-----------|--------|-------------------------|--------|
| India (Census)      | 1.08 bn          | 21.90 mn       | 2.13                              | 48.55  | 7.49   | 5.76    | 27.87     | 10.33  |                       |        |
| India (NSSO)        | 102.72 mn        | 18.49 mn       | 1.8                               | 13.6   | 10.37  | 14.73   | 51.19     | 10.08  |                       |        |
| Pakistan            |                  | 132.3 mn       | 3.2 mn                            | 2.42   | 8.06   | 7.43    | 6.39      | 18.93  | 7.6                    | 8.23   | 43.37 |
| Bangladesh          |                  | 152.6 mn       | 1.43 mn                           | 0.97   | 17.55  | 2.55    | 21.05     | 43.55  | 15.3                   |        |
| Bhutan              |                  | 0.6 mn         | 6,881                             | 1.05   | 18.94  | 6.71    | 49.47     | 14.23  | 6.49                   | 2.44   | 1.71 |
| Sri Lanka           | 0.9 mn           | 71,935         | 8                                 | 16     | 13     | 20      | 14        | 21     | 16                     |        |
| Maldives            | 0.3 mn           | 4728           | 1.53                              | 14.96  | 16.4   | 22.51   | 18.35     | 12.54  |                        |        |
| Nepal               | 22 mn            | 0.01 mn        | 0.46                              | 15.9   | 24.6   | 39.3    | 12.7      | 7.5    |                        |        |
| Afghanistan         | 29 mn            | 0.08 mn        | 2.71                              | 25.5   | 36.5   | 9.7     | 9.4       | 18.8   |                        |        |

| Total populn | Total disabled | Disabled as a percentage of total | Visual | Deafness | Locomotor | Mental | More than one | Others |
|--------------|----------------|-----------------------------------|--------|----------|-----------|--------|---------------|--------|
| Nepal        | 22 mn          | 0.01 mn                           | 0.46   | 15.9     | 24.6      | 39.3   | 12.7         | 7.5    |
| Total        | Total          | Disabled as a percentage of total | Sensorial | Physical disability | Mental | More than one | Others |
|              |                |                                   |         | (crises, epilepsy) |         |              |        |
| Afghanistan  |                |                                   |         |          |           |        |              |        |

| Rural | wheelchair | artificial limbs | crutch | splint | tricycle | Calipers | spinal brace | others | n.r. |
|-------|------------|------------------|--------|--------|----------|----------|--------------|--------|------|
| Purchase | 129        | 342              | 2723   | 351    | 64       | 608      | 112          | 1706   | 97   |

Table 1: Total population, total no of disabled and types of disability (as percentage of total disabled) for SAARC nations. Pakistan Census, 1998, Bangladesh Census, 2001, Household survey on disabilities by Bhutan Health Department, 2002, TEAMS: Final report of the study of Physically Impaired people of Sri Lanka, Public Investment Plan 1996-2000, 1996, Maldives Census, 2002, National Planning Commission and Central Bureau of Statistics, Nepal, National Disability Survey, Afghanistan carried out by Handicap International, 2006.

Rehabilitation Scenario for the Locomotor Disabled in India

We would proceed to look into the rehabilitation environment for the locomotors disabled, the largest category among the disabled in India for a representative sampling, on the basis of the data generated by the National Sample Survey (Central Statistical Organization, India) 58th round done in July-December, 2002 [6]. Out of the 1000 persons with locomotor disability prescribed for assistance, 149 and 204 for the rural and urban classes has received aid in the form of wheel-chair, artificial limbs, crutch etc. However, despite the fact that the number of locomotor disabled in rural areas is thrice that in the urban category, the acquisition rate is much greater in cities. For a poor nation this means that rehabilitation programmes have concentrated in relatively well-offish area and failed in its reach-out target. The recipients have received government assistance mainly in the acquisition of generalized mobility aids as wheel-chairs and tricycles and crutches while most of the case-specific acquisition of prosthetics and orthotics has been from outright purchase (Table 2).
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Table 2: Distribution of recipients by source of acquisition for type of aid/appliance (in’00). Source: NSS Report 485(58/26/1) pages A-430 and A-433.

| Source          | Purchase | Govt assistance | NGO assistance | Others | N.R. |
|-----------------|----------|-----------------|----------------|--------|------|
| Urban wheelchair| 151      | 176             | 59             | 13     | 5    |
| Purchase        | 238      | 142             | 80             | 12     | 10   |
| crutch          | 1201     | 80              | 159            | 0      | 0    |
| splint          | 167      | 7               | 0              | 0      | 0    |
| tricycle        | 51       | 20              | 7              | 0      | 0    |
| Calipers        | 485      | 100             | 82             | 16     | 0    |
| spinal brace    | 63       | 5               | 4              | 48     | 1    |
| others          | 767      | 5               | 13             | 269    | 0    |
| N.R.            | 74       | 105             | 5              | 22     | 1    |

So what happened to the rest of the locomotor disabled population? Out of 1000 locomotor disabled advised assistance, 149 received aid in rural category, 851 did not (6.79 million). And 204 out of 1000 in urban category received aid, 796 (2.11 million) did not. Among the recipients, 77% use it regularly. The rest do not: as they find it uncomfortable for use (47.8%), find difficulty in maintenance and repair (9.7%), 42.4% do not use it for other reasons (NSS Report page A-463).

As is expected in the backdrop of a developing nation, staggering high figures reported (49% of the people prescribed aid) that they found the aid/appliances expensive for their pocket and could not acquire it thus. It we treat India as a sample for the total SAARC population; we expect the same rehabilitation environment to prevail in the poorer nations of the cartel, barring Sri Lanka.

Questioning the Functioning Of CBR in Poorer Nations

In 1970 the World Health Organization (WHO) introduced Community based Rehabilitation (CBR), a new approach to disability rehabilitation. It targeted to provide rehabilitation services for all disabled irrespective to their income level at their place of residence. The concept arose due to “the serious mismatch in the allocation of human and financial resources devoted to disability rehabilitation” [7-10].

Community Based Rehabilitation (CBR) is designed to operate at Community, District, Provincial and Central levels. It aims to build up resources from the grass-root community plinth. It has three stakeholders, the government organization, the non-government organization and the PWD [11]. CBR in India operates in a non-institutional setting run mainly by non-government organizations.

In the post-liberalized economic era, as the state has retreated in the realm of privatization, the NGOs have moved in to fill the vacuum. The NSSO (63rd round, 2006-2007) survey has indicated a 40th per cent increase in the number of social service organizations in the ongoing decade. However, the number of service units working towards PWD rehabilitation has not been made available by the survey.

The accountability of NGO operation has been challenged fiercely. A survey “Giving in India” conducted by “Help Age India,” an NGO itself has questioned the service sector for remaining opaque on its sources of fund, the amount and its utilization.

Though most of the funding has come from domestic sources (government being the largest donor), foreign donations also made up a significant portion of the resources available to NGOs. However, despite a Foreign Contributions Regulation Act, no authentic figures on foreign donations were made available with the government.

The CBR in India is run by NGOs that prevail in a sector that has remained under-mapped, unaccounted and unaccredited over long years. Though guidelines are issued towards formulating the basic working premises for CBR, it has seldom been checked for viability. Unless a thorough cost-benefit analysis is run on CBR, the system will eventually render itself to strong criticism and trigger a series of hostile responses. We question the feasibility of CBR in India and take up two courses of action to do this.

We would cull data from the Ministry of Social Development and Empowerment Web-site for funds disbursed to NGOs working in different states, administrative divisions within India, for years 2004-05 and 2009-10 towards disability rehabilitation. The years are so chosen to monitor the movement of funds on the fifth and the tenth year of the publication of the 2001 population census to understand the trend reflected in the decade that just passed by. A normative economic judgment would expect the fund flow to each state to be correlated strongly to (a) the disaggregated state disability figures, culled from Census, India, 2001 tables; (b) the percentage of disabled population in each state with respect to the total state population; We would see whether that has been the case. We would search for other determinants that might have governed the disbursement of grants-in-aid to different states to adjudge the feasibility of CBR.

Was the Rehabilitation Fund Allocation Need Based?

We run a correlation with the government disbursement towards disability rehabilitation in 2004-05 and 2009-10 with (a) the number of PWD in the state (b) the percentage of PWD in the state to the total state population using the SPSS software. Taking both (a) and (b) as
independent variables and fund disbursement as the dependent variable we run regression on the data to look into the causal relationship between the two variables [11].

A strong positive correlation coefficient, statistically significant regression results with high r2 will authenticate the CBR philosophy of providing rehabilitation services irrespective of the PWD income level at their places of residence. A deviation from the expected result will, however, raise questions towards the feasibility of CBR. The explanation of the correlation results are as follows: The degree of association between the funds disbursed to state NGOs for PWD rehabilitation and the number of disabled in the state are weak and statistically not significant. This is against the normative judgment that expects more funds to flow to states with more PWD and definitely against the CBR philosophy which advocates for rehabilitation of the disabled at their place of residence. The values of r2 are too weak, indicating that relative amount of variation in the dependent variable (flow of funds to states) could not be statistically explained by the independent variable (the number of disabled person in each state or the percentage of state PWD to state population) in 2004-05 and 2009-10. The results of these exercises are presented in Table 3. (The background data for this exercise is presented in Table 4).

| Degrees of association, causal and otherwise | 2004-05 funds | 2009-10 funds | Spearman's rank |
|---------------------------------------------|---------------|---------------|----------------|
| With the number of PWD in state as a variable | Correlation coefficient | 0.382 | 0.46 |
| | r2 (Proportion of variation explained by regression) | 0.126 | 0.182 | 0.72 |
| With the percentage of PWD in state to state population as a variable | Correlation coefficient | -0.013 | 0.03 | 0.54 |

Table 3: Correlation Coefficients, Proportion of variation explained by regression with 2004-05, 2009-10 funds. (Spearman's ranks significant at both 0.05 and 0.01 levels).

Other Factors Governing PWD Rehabilitation Fund Allocation

We proceed to look for some alternate determinants governing the fund dispersal mechanism. It has been pointed out in the Social Development Ministry Web-site that “the presence of non-government organizations is not uniform throughout the nation. Similarly, there are certain spheres of activities that attract more voluntary organizations just as their concentration in some regions.” This has resulted in the disparity of development across states as well as across sectors. However, what governs this asymmetric performance pattern of NGOs across Indian states?

Majority of private sector units worldwide tend to conglomerate in sectors where operations are comparatively easier than their public sector counterparts. They unmistakably plan to set up shops in states with better infrastructure, with better facilities for upcoming industries. In short, the immediate profit-maximizing motive dominates the decisions of private sector units, while the public sector has some social considerations along [12-14].

This thread of observation has been picked up and extended here in this paper to question whether the NGOs followed an identical pattern of operation. In the absence of data on the quality performance of NGOs in a state, the strength of correlation of state HDIs [the dummy for the overall well-being of the state] is ascertained with the funds disbursed towards each state for disability rehabilitation.

The methodology has been as follows: We have assigned two sets of ranks to each state, one the HDI rank the other according to the fund disbursed to NGOs. We have calculated the Rank Correlation, using the Spearman's Rank Correlation formula (Table 4).

| States          | HDI values 2001 | Funds to state NGOs in '04-05 (in Rs million) | HDI values 2006 | Funds to state NGOs in '09-10 (in Rs million) | No of PWD in states (in million) | Percentage of disabled population of state to total state population |
|-----------------|-----------------|---------------------------------------------|-----------------|---------------------------------------------|---------------------------------|---------------------------------------------------|
| Andhra Pradesh  | 0.416           | 74.85                                       | 0.585           | 14.65                                       | 1.36                            | 1.78                                              |
| Arunachal Pradesh | -              | 0.31                                        | 0.647           | 0                                           | 0.03                            | 2.75                                              |
| Assam           | 0.386           | 0.46                                        | 0.595           | 32.75                                       | 0.53                            | 1.99                                              |
| Bihar           | 0.367           | 0.51                                        | 0.507           | 0.89                                        | 1.88                            | 2.27                                              |
| Chhattisgarh    | -               | 0.43                                        | 0.549           | 0.75                                        | 0.42                            | 2.02                                              |
| Gujarat         | 0.479           | 27.79                                       | 0.634           | 5.78                                        | 1.04                            | 2.05                                              |
We find the two sets of ranks to be strongly related in this case. So the fund dispersal has been inequitable. Instead to flowing to where it is needed, it has trickled to where the work environment in conducive. This is definitely against the working philosophy of CBR [15].

Borrowing from the famous Poverty and Famines: An Essay on Entitlement and Deprivation (1981), we can argue that the rehabilitation environment has not only been affected by paucity of funds, but from inequalities built into mechanisms for distributing it like bottlenecks in supply chain, asymmetric information, mismatched demand supply. As these asymmetries characterize underdeveloped countries, we can safely assume that the lacuna in disability rehabilitation exists in the other lower-middle income countries of the SAARC region as well.

**Conclusion**

The recent UN convention on rights of the person with disabilities (UNCRPD) has reiterated the fact that disability is above all a human rights issue [Article 3(g), Article 3, 7(children with disabilities)]. The medical model of the International Classification of Functioning and Disability (ICF) [16] views disability as 'a problem in functioning of a person, directly caused by disease, trauma or other health conditions, which requires medical care provided in the form of individual treatment by professionals.'

From the social scientists' point of view, the capability approach [13] sees human life as a set of functioning, e.g. escaping morbidity and mortality and taking part in the life of the community. If we very crudely try to relate Sen's capability approach to the ICF model, the term 'functioning' as used in ICF can be used synonymously as 'capability', 'disability' as 'capability failure', 'improved functioning' would imply 'development' [12].

Despite robust economic growth, the success of India in the field of development paradigm, especially in the rehabilitation performance of the PWD has been limited. The feasibility of CBR has been under question. We have failed to enlarge people's choices, failed to create an enabling environment for the disabled in India. Actual development has dwelt on the periphery of the problem, leaving the core untouched. The generalized rehabilitation programme has robbed the disabled of the chances of being individually treated by professionals. The failure has been sharper when follow-up measures on the first course of action taken have been taken into consideration.

We might be disappointed at our failure, but we are doomed if we do not try.
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