



REHABILITATION FOR DISABLE PERSONS

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ABSTRACT

This article discusses the role of culture and traditions in the shaping of disability rehabilitation in India. Social and religious institutions guided by the charity model played a pivotal role through history, in providing essential care to the needy. In India, religion and family have remained at the core of community life. This article argues that CBR should draw its strength from religious institutions and thrive on their immense resources. There is a need to have a harmonious blend of tradition and modernity to seek community participation for rehabilitation programmes. Many disability NGOs have lately started moving in this direction to mobilise local resources and to reach out to the millions who have no hope of a better life otherwise.

INTRODUCTION

As Groce (1) argued, the rehabilitation practices of a society cannot be understood without making sense of its cultural beliefs and coping mechanisms. Societies develop their characteristic patterns of coping with physical disability, depending on the way disability is understood and their resources then identified. Historical events, sacred texts, social institutions, and so on, all contribute in the social construction of disablement. In this endeavour, it is imperative that culture and traditions are viewed as strengths rather than impediments in improving the quality of life of people with disability. This article examines traditional approaches to disability rehabilitation and their relevance in the changing social scenario in India.

Culture is an amorphous term, used differently in different contexts. One can focus on Indian culture as distinct from western culture in terms of defining disability and its implications, for national policy and programmes. However, India being such a vast country, it is difficult to think in terms of a unified-single culture that is prevalent everywhere. Indian society has always remained pluralistic with multiple traditions weaving a multi-coloured pattern. In the past, waves of immigrants with different faiths and cultures, not only contributed to the dominant Hindu view of disability, but also preserved their unique heritage (2). It is important to note that these were living traditions with a history of dissents, protests and reforms, and efforts to adapt to the new realities. In the resulting diversity, two factors, which were common to all traditions and which survived many crises, are family and religion. These were the decisive factors that played a role in shaping the rehabilitation practices of society. Family, as a basic social unit played its crucial role in uniting and supporting its members and giving them a social identity. Like family, religion also pervaded all spheres of life, as a major force behind all social decisions and activities. This scenario has not changed much in spite of all global, economic and technological changes affecting the local communities. Understanding the socio-economic background of these families, which comprise local communities and their



religious practices, is essential for the success of any rehabilitation programme at the grassroots level.

In recent times, rehabilitation policies and programmes are increasingly emphasising participatory models. Unless there is a knowledge and understanding of the local culture, no community based scheme can succeed in mobilising local participation. Any discussion on local culture can thus have a twin objective. The first is to ensure active participation of the local communities at all levels of programme planning and implementation, and secondly, to identify indigenous knowledge and resources, in achieving the ultimate objective of improving the life conditions of people with disabilities and their families. In this article, religious beliefs and family practices will be closely examined in the light of the findings of recent researches conducted by the author.

THE CONCEPT OF DIVINE RETRIBUTION

Indians, in general, have an ambivalent attitude towards people with disability. In dealing with someone with a disability, people are caught in an avoid-help kind of a conflicting situation and feel anxious. The religious beliefs about disability only add to this confusion. There is a belief in divine punishment in all religions and people tend to accept the condition of disablement as something they deserved. This punishment is presumed to be meted out for their sinful acts, and one can overcome the resultant suffering by engaging in morally right behaviour. The other prevalent notion is that God inflicts suffering on good people to test their resilience and inner strength. In either case, one is expected to respect God's will. Those people who are more fortunate are exhorted by religious texts to show pity and compassion to all those who are suffering. Manu Smriti, the ancient charter of social conduct impelled people to spare a part of their material resources for their hapless fellow-beings; to support their daily living (3). Dharmashastra called upon all householders to look after the weak and disabled, and those who did do so, were ensured a place in heaven (4). Such care was to be shown without expectation of any returns.

Hindu scriptures have provided elaborate commentaries on 'why do people suffer?' The theory of Karma is propounded to explain all kinds of suffering. This theory implies that if one has committed misdeeds in previous births, one has to inevitably bear the consequences. Disability is held to be a punishment for the sins of previous births and one is called upon to accept it as divine retribution. This notion of a just world is firmly ingrained in the Hindu mind and is frequently invoked to explain whatever happens in one's life (5, 6). Belief in the theory of Karma has very often led to a ready acceptance of physical disability, with little effort in the direction of improving life conditions. It is presumed to be a deterrent to collective efforts put in by persons with disabilities to assert their right of equal access to social opportunities.

So strong was the belief in Karma as a potent cause of all human suffering throughout the ages, that people with disability were never identified as a separate



group, nor were they segregated on this count. In most of the earlier literature (3) destitute, widows, aged, diseased and disabled people were put together. The shelter homes built by benevolent kings and nobles were for the benefit of all those who had no other place to go, whether their problem was social, economic, or physical. This practice continued all through the medieval and colonial era. So much so, that even in the constitution of free India they were bracketed together. Article 41 of the Indian constitution adopted in 1950 reads, **"the State shall, within the limits of its economic capacity and development, make effective provisions for securing the right to work, to education, and to public assistance in cases of unemployment, old age, sickness and disablement"**.

Some of the studies conducted by the author and his colleagues have clearly shown that people frequently do attribute their disease and disability to metaphysical factors, particularly to their own Karma. Dalal (7) studied causal beliefs of hospital patients who were under treatment for a wide range of physical diseases - coronary heart disease, tuberculosis, cancer and orthopaedic problems. These patients consistently attributed their physical problems to their own Karma. In general, causal attribution to metaphysical factors (God's will, fate and Karma) was consistently high. These patients, however, did not attribute their recovery to their Karma, as much as to the doctor, God and other factors. It may be mentioned here that most of these patients were rural, uneducated and from poor families. Similar findings were also obtained in the case of physical disability also. In a study conducted in rural areas, Dalal, Pande, Dhawan and Dwijendra (8) found that people with disabilities, their families, as also other community members more often attribute physical disability to cosmic factors: fate, God's will and Karma. Religious beliefs thus seem to be providing important explanations for both diseases and disabilities.

Such causal profiles may lead to the erroneous conclusion that these people are irrational, passive, fatalistic and "otherworldly". When one attempts to view the situation as an insider, the pertinent question would not be one of fatalism but would relate to the structure of opportunities. Poverty, lack of medical facilities, poor hygiene and un-supportive Government machinery puts them in a predicament where their efforts prove repeatedly futile. Also, when the existing body of knowledge and technology fails to provide solace and the outcome of their efforts are negative, people learn to accept the outcomes in a spirit of resignation (9). When fresh opportunities did surface, or when new technical choices were available, the same people did not lack initiative in trying them out. Joshi (10), in a study of tribals in the foothills of the Himalayas observed that people are pragmatic in their causal attributions. When they see a medical doctor for their sickness, they talk about the organic symptoms, but the same people visiting a traditional healer articulate their sickness in terms of metaphysical causality - God's wrath, spirits, etc. The patients intuitively learn to keep these two aspects of the disease separate. Kleinman (11) in his extensive work in China, India and other Asian countries found that in all these places, traditional healing and biomedical treatment co-exist and are not perceived as contradictory.



Though the meaning of the principle of Karma has a different connotation for different people in different contexts, the belief helps people in accepting their own (and others') suffering. The belief in Karma is so deeply ingrained in the minds of the people, that any effort to dismiss or dislodge it can be counterproductive. There are, indeed, many misconceptions about what this belief does to a person. It is argued that the acceptance of disability as Karma (or due to cosmic causation), gives people some explanation for their suffering, which cannot be justified otherwise. Janoff-Bulman and Wortman (12) also showed in their study of paraplegic patients that those who had an explanation for their tragedy, were better off than those who had no explanation whatsoever. These metaphysical beliefs prepare people to face the adversities on one hand and to sustain hope on the other hand (6, 13). As noted by Paranjpe (5), belief in Karma keeps the faith in a just world alive, even under very adverse conditions, and reinforces hope that good deeds will ultimately result in good outcomes. Dalal (7) also discovered that in the case of hospital patients, attribution of their disease to Karma had a positive relationship with their psychological recovery. In fact, we are only recently beginning to understand the positive role of religious beliefs and these cannot be dismissed as just impediments in rehabilitation programmes.

This all-pervasive faith in supernatural powers as potent causes and remedies for disabling diseases has led to the proliferation of healing centres in the country. These healing centres have retained their popularity throughout the ages and are visited by a large population. Cutting across all cross-sections, people believe in the healing powers of these shrines and frequent them regularly in hope of a miracle.

ASHTAVAKRA : AN INDIAN ARCHETYPE OF DISABILITY

The story of Ashtavakra can be cited to highlight the Indian archetype of disability and the faith, which it bolsters in traditional healing. This story is referred to in many ancient texts, including the Mahabharat. Ashtavakra was the only son of sage Kahod. Kahod was a learned scholar and a teacher of the Holy Vedas. One day, when Kahod was teaching the Vedas to his disciples, Ashtavakra, who was still in his mother's womb, chided his father for misinterpreting the Vedas. Kahod felt insulted before his disciples and in a fit of anger cursed the foetus to be crooked in eight parts of the body. Ashtavakra was thus born with physical disability.

Kahod was very poor, and so one day he decided to go to king Janaka for help. On the way he met the King's courtier Vandin who challenged and defeated Kahod in a debate. As part of the deal Kahod forfeited his life. Ashtavakra was brought up by his mother who moved to her father's house. There, Ashtavakra was looked after by his grandfather whom he mistook for as his own father and his uncles as his brothers.

When he was 12 years old, Ashtavakra realised who he was and why his father met a tragic end. To avenge it, he started for King Janak's court but was denied entry by the king's officials. They ridiculed him for his deformities. Ashtavakra asserted his right of way and reprimanded the king saying that only people of a lower



order care for flesh and bones and ignore the inner qualities of the person. He answered all the questions put forth by the king and got admittance in the court. There he challenged Vandin to a debate on the essence of religion and defeated him. The humbled Vandin promised to bring his father back. The father regretted what he had done to his son, and advised him to take a dip in the holy river. Soon, all Ashtavakra's limbs got straightened and he came out as a handsome man.

The story brings out many facets of disability in the Indian setting. The symbolism of people with disability as children is a typical cultural theme. It denotes a parent-child type interaction pattern in all social relationships with people having disabilities. In traditional Indian families, children are the shared responsibility of everyone. The children are considered dependent, immature, and incapable of taking decisions about their own lives. The family takes it upon itself to meet the basic needs for security, food and affection of all the children. The adults of the family have a patronising attitude, which was evident in research data also (14). Unless they doubly prove themselves and assert their rights as equals, these children of the lesser gods are rarely taken seriously.

Another aspect of disability implicit in this story, is the guilt which parents suffer for the disability of their children. Often, they consider themselves as responsible (in a metaphysical sense) for all the suffering of their children, about which they can do nothing. The Karma principle is invoked to argue that people have to accept the condition of their birth. Related to this is the message that there is always a possibility that things will improve in the future. This positive orientation further bolsters the faith that people with disability can achieve as much, or even more than other people do. Indian mythology and history are replete with instances wherein people with disability had out-standing achievements.

FAMILY BASED REHABILITATION

In India, disability rehabilitation is primarily considered to be a responsibility of the family. Large and extended Indian families provided essential physical, emotional and economic support to its members with disabilities. Being cohesive and stable social units, families provided an identity and a sense of security to its members, irrespective of their physical disabilities. The economic and caste status of the family and its networks, also determined the quality of the well being of its members with disabilities.

The concept of rehabilitation in its modern sense did not exist in these traditional families. The care provided was mostly routine and of a maintenance type. The responsibility was shared by all members of the family, ensuring life-long social and economic support. All major decisions about property, marriages, and education were taken collectively, keeping the interest of the family uppermost. People with disability as individuals, had hardly any say about their own future. They lived just like others in the family. Disability neither undermined nor enhanced their status. Everyone had a place in family hierarchy and was bound to others by role relations.



The sense of belonging was the most cherished goal and any threat of isolation, or of social proscription was considered the worst thing to happen to anyone.

Such family practices worked well, as Indian society had remained agrarian all along its past history. Agriculture was not only the means of livelihood and economic mainstay of society, but was also a way of life. As agriculture used to be a collective activity, most of the family members were involved in some role and contributed to the family income. There were no individualised jobs, no personal income; they jointly shared the fruits of their labour. Another notable feature was that the place of work and the place of residence were mostly the same. This was true for a whole variety of occupations, which were caste based and hierarchically arranged. Work was a way to reaffirm one's sense of belonging to a social group. As a result, those who were restricted by a disability did not feel handicapped in a joint family occupation. They could set their own schedule and pace of work while others were always available to extend a helping hand. Social and occupational integration was thus rarely a problem for those who lived with family.

The jobs were few outside the family fold. Some jobs were specially marked for people with disabilities. For example, persons with hearing and speech impairment were preferred as attendants by kings and nobles (15). This would guarantee that activities and conversations that took place within the palace would not be passed around. This practice was fairly widespread since ancient times. Certain occupations were reserved for visually handicapped people. In south India, the preparation of flower-garlands, which were in much demand for domestic and religious purposes, were mostly reserved for women with blindness. Among north Indian Hindus, many visually impaired persons practised vocal and instrumental music in temples and worked as music teachers. Among Muslims, visually handicapped people earned a livelihood by teaching and reciting from the holy Quran. People with orthopaedic disability were considered normal for a variety of jobs. Those who had severe deformities (or dwarfs) were considered fit for the circus and as court jesters.

Local communities played an active role in supporting orphans, destitutes and those who had been deserted. The community concern was evident in the establishment of many social and religious institutions, providing basic care to people with disabilities who had nobody to turn to. These charity institutions survived on public funding, which was occasionally bolstered by kings and nobles. Such community support used to be spontaneous, as part of the culture of communal caring and sharing. Several such organizations survived for hundreds of years and many of them exist till today.

THE COLONIAL EXPERIENCE

With the colonisation of India by the Britishers, large scale missionary activities started with official patronage. These charity institutions followed the same philosophy and practices, which they brought along from the west. Miles (16) has documented many disability institutions, which were established in different parts of



the country. These charity based organisations worked with missionary zeal to spread the message of Christ, of love and kindness. The benefactors had complete control over the lives of the inmates in these institutions. The beneficiaries were held as 'tabula rasa', as if they had no language, no culture, no preferences, or, that these aspects were not worth considering. The indigenous culture and belief system was completely ignored. The divide between benefactors and beneficiaries, did help in reaching out to the poor and destitute but made no substantial impact on the disability situation. These attitudes eminently suited the colonial rulers who had but little respect for the local culture. The political, educational and economic institutions they created aimed primarily at consolidation of their colonial rule. Disability was never a real issue for them to bother about.

The industrialisation sweeping the west was bound to make inroads in India as well. Urbanisation and industrial growth brought about a change in the concept and place of work. The capitalist economic model placed a greater value on a private individual being able to make a productive contribution to the market economy (17). People with disability were perceived as non-productive members of society. This ideology was in direct conflict with the traditional ethos and affected the status of people with disability. In the long history of colonisation, the Indian elite exposed to a western world-view, blindly followed their rehabilitation practices. As Mellory (18) puts it, such residual attitudes were being reinforced as post-colonial developing countries continued to support policies and practices of the Christian missionaries. The western system of education also proved a potent tool to assimilate the value placed on individual achievements in the west.

THE NEHRUVIAN MODEL OF A WELFARE STATE

In the post-independence era, Nehru became the Prime Minister and the Nehruvian model of a welfare state was the guiding principle in all social development programmes. The government took upon itself the onerous task of providing rehabilitation for all and the Government bureaucracy was deployed to plan and implement rehabilitation programmes. This has led to a phenomenal growth of centralised and institutionalised services for the welfare of people with disabilities in the first two decades of independence. The Ministries of Social Welfare at the Centre and state level played a major role in framing policies and programmes and infrastructure development. A National Council of Handicapped Welfare was set up to frame policy guidelines for the entire country and to prioritise disability programmes. This Council, comprising Central and state ministers and rehabilitation experts, regulated the activities of the Central and state governments and of voluntary sectors. However, due to differences in commitment, in some states the welfare programmes were well developed with substantial funding like in Bengal, Gujarat, and Maharashtra, whereas in other states (like Uttar Pradesh) the programmes were rudimentary and starved of funds.

The Central and state governments initiated a large number of welfare schemes and enacted laws to monitor the functioning of governmental and non-governmental agencies. Four national institutes for four types of disability, blindness,



orthopaedically handicapped, hearing impairment and mental retardation were established in different parts of the country during this period. All these national level institutes were intended to serve as apex bodies in the respective fields of man-power development, evolving suitable service models, carrying out research and serving as information and documentation centres. The Government also set up 11 regional vocational training centres in different parts of the country. The State governments and voluntary groups founded many other training organisations. To ensure uniform standards in technical courses in the field of rehabilitation for the disabled, the Government of India set up in 1986, the Rehabilitation Council of India, based upon the model of the Medical Council of India.

Most of the rehabilitation services in India followed the biomedical model in which hospitals and primary health centres played a key role. Disability was viewed as a disease state and the emphasis was to cure, correct, or ameliorate the problem so that persons with disability became as "normal" as possible. The focus was on disability, which was perceived as an individual problem to be handled by competent medical experts. This perspective was compatible with the welfare model and was well suited to the international funding agencies, including WHO and UNICEF. People were, in fact, treated as passive recipients of welfare services which primarily concentrated on free distribution of medical aids and appliances to the poor and needy. These practices only reinforced the culture of dependency. Given the magnitude of the problem, poor resources and infrastructure, these schemes hardly had any impact, reaching out to only 2-3% of the needy population.

THE DECADE OF DISABLED PERSONS

It was in the '80s, that there was a move to evaluate afresh the state of disability in India, and to search for alternative models of integrating people with disabilities in the social mainstream. During this phase there was also an ideological shift in the developmental planning - from welfare to human resource development. The idea was that, rather than making people recipient of state welfare, people should be viewed as a human resource and should be fully developed through education and training. The National Committee on the International Year of the Disabled Persons was set up under the chairmanship of the Prime Minister. Many working groups and task forces were set up by central ministries to give high priorities to the action plans for the people with disability.

The Decade of Disabled Persons (1983-92), marked another shift in the whole debate about the goals of rehabilitation. There was a dawning realisation that neither charity, nor welfare, nor a human resource development model could succeed in a country like India. The view that rehabilitation services need to be community based was gaining support from all quarters. There was no way the government and non-government agencies could meet the challenge of vast rural disability. There was a need to mobilise local resources and support to sustain disability rehabilitation programmes. Second, was the increasing involvement of international organisations in national programmes on disability. Many major projects were funded by international agencies. The Government found it an easy way to generate much



needed finances to run various programmes. Often, western models and theories become part of the funding package, which ran counter to the realities of the traditional world. International agencies indeed brought a change in service culture, ideology and ways of functioning of governmental and voluntary organisations. Today, service organisations are in the throes of a major transition as they are aligning more and more with international movements.

A major event in the recent past, was the enactment of the Persons with Disabilities Act, 1995 (19), by the Indian Parliament. This comprehensive law ensures equal opportunities, protection of rights and full participation of people with disabilities in all spheres of national life. With this, the Government has done away with charity and welfare based models of rehabilitation. The Act has guaranteed equal rights, with provision of imprisonment for those who indulge in discriminatory practices. It is a different story that, though the Act was signed by the President of India and came into existence on February 3, 1996, it took the Government about three years to take necessary follow-up steps to make the Act fully operational.

PARTNERSHIP FOR DEVELOPMENT

The disability scenario is rapidly changing in India. The efforts of the last many decades have brought a qualitative change in the lives of many people with disabilities. There is now a large section of people with disabilities who are educated, professionally successful and in leadership positions. Many of them are quite active in advocacy roles and are asserting their right to participate in all decision-making affecting their lives. International exchange and collaboration have made them aware of the struggle of people with disabilities in other countries. This upwardly mobile strata of society is playing a key role in advancing the disability movement in India. They are also claiming equal partnership for people with disabilities in all development programmes affecting their lives. Though the partnership model appears incompatible with the traditional practices, the success of partnership practices in the recent past is a clear indicator of changing attitudes of society, the Government and service organisations.

CULTURAL BELIEFS AND CBR

In the last two decades, community based rehabilitation (CBR) has been promoted as the most viable and practical solution for the massive problem of disability in India. It envisages a social environment in which a community shows awareness and sensitivity to the special needs of its disabled members and feels responsible to bring about the desired changes. To achieve this ideal and to sustain such programmes through the community's own resources and active participation, ambitious schemes were launched in the mid-eighties by the Government and NGOs. A large number of CBR projects were generously supported by the Government and international agencies. All these efforts in last two decades have contributed to popularise the philosophy of CBR and in raising the hope of the millions of people with disabilities.



Hopes for the efficacy of CBR, lies in the fact that a strong sense of community has always remained a strength of Indian society. For thousands of years, local communities have taken care of their members with disability. In the long run, these local communities evolved their own systems of managing physical disabilities within their own resources. Religious centres (temples, mosques, shrines, etc.) have served as nodal agencies around which local resources were mobilised and rehabilitation services were organised. This practice continues even today in many places.

However, in its present incarnation, CBR is a product of the western scientific tradition. Conceived by international agencies and adopted by some urban NGOs, CBR was carried to Indian villages as a package of promises. It is a package made of western positivism, individualism and secularism and shaped by the biomedical theories of health. CBR, as practised in India, clearly reflects biases of the urban, educated, social activists and that of the funding agencies. CBR initiators carefully maintained their distance from the religious institutions and other traditional organisations. For them religion becomes an anathema, as they pursued the goals of CBR that fit within a medical and scientific framework. The emphasis is on need survey, advanced planning, budgeting, record keeping, outcome evaluation, etc. All these are not only alien but also incompatible with the informal village functioning.

One of the peculiar things about most of the CBR programmes in India, is that these programmes are rarely planned keeping in mind the disability beliefs, practices and conditions of the local communities. These CBR programmes are rarely built on cultural strengths of the local communities. It is otherwise, unexplainable as to why community participation is not so spontaneous for CBR activities, as in the case of social and religious events. Religious beliefs influence all aspects of social life in Indian villages (20, 21). It is still the single most unifying and motivating force in otherwise fragmented village communities. The secular CBR programmes failed to catch the imagination of the masses and have failed to ensure active community participation. In an evaluation study of seven major CBR programmes of the country, Dalal, Kumar and Gokhale (22) found that CBR programmes have not fulfilled their promises and are primarily viewed as service delivery agencies by the local people. The study showed that often CBR programmes sustained as long as the outside funding lasted. The local participation in these programmes is mostly confined to attending camps, meetings and training programmes. With all non-governmental and governmental support, CBR has failed in bringing about any significant change in the disability scenario in rural areas.

CONCLUSION

The success of a CBR programme in India will largely depend on how much they can draw from traditional sources. In a country like India where religion pervades all domains of life, there is nothing wrong if CBR draws its strength from religious institutions and can access their immense resources. If CBR can be integrated with social ceremonies, festivals and rituals, community participation will come naturally. Many NGOs are now trying to involve spiritual leaders of different



faiths in social and developmental programmes. CBR, grown in a soil having a proper mix of tradition and modernity, is more likely to become a grassroots movement and succeed.

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