



Disability studies and scope for rehabilitation of differently abled children

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ABSTRACT

Disability Studies has offered us critical approaches with which to re-think and re-assess existing research tools and methods in any discipline. Examining existing bodies of knowledge from the disability perspective; collating, understanding and analyzing the construction of disability; providing voice to the lived experience of persons with disabilities and acknowledging their experiential expertise could be some of the overarching objectives to prompt disability studies. However, while education is recognized as a pathway of moving out of poverty, there is very little focus on how children with disabilities can be effectively included into the education system. While India is seen as having one of the most progressive education policies in relation to children with disabilities, evidence reflecting on the educational participation and effectiveness of schooling for this group of children has not been a focus of disability research. In this paper drawing insights from field practices, an attempt is made to chart out the role of disability studies, to not only define a research agenda from the perspective of persons with disabilities, but also the role of research itself in emancipating the lives of poor persons with disabilities by influencing policy/environment change. In fact, it also underscores the need to incorporate the unique concerns and experiences of disabled people while designing and practicing research in the field of disability studies in India.

Keywords: disability studies, differently abled, children

INTRODUCTION

Historically, the problem of disability is as old as human civilization. There were several instances in history when people with disabilities played significant role negative or positive in society. In primitive societies, disability was considered as a curse of God or punishment of God for wrong deeds done in past lives. Consequently, disabled were treated as aliens and were isolated and rejected. They were denied basic human rights such as the right to live in mainstream society. They were either put in shackles or sent to isolated confinements. The families having a disabled member were seen with suspicion. In turn, to avoid public fun and humiliation, disabled were kept hidden with their families.

Examining existing bodies of knowledge from the disability perspective; collating, understanding and analyzing the construction of disability; providing voice to the lived experience of persons with disabilities and acknowledging their experiential expertise could be some of the overarching

objectives to prompt disability studies. The translation of these overarching objectives on the ground would vary according to the spatial situation of the centers for disability studies. exclusive stand-alone centers; centers in multi-disciplinary and centers in single discipline universities would have different operational trajectories.

Just like Gender Studies, Queer Studies and several other emerging areas of studies, particularly the ones related to marginalized sections of society, Disability Studies is also one of the emerging areas of studies in a few parts of the world. It has its roots in activism. It continues to remain highly marginalized areas of study in the academic discourses in most universities in the world. But lately there has been a ray of hope for the creation of a fertile ground for its emergence due to a few developments since the 1970s.

Disability studies (DS) in Britain and the US developed, from the 1970s onwards, both as a counter to hegemonic medical models of disability that continue to frame international discussions of disability, and in relation to particular histories of industrialization and civil rights movements. While western disability studies has usefully charted a course that institutions keen to embrace the study of disability elsewhere in the world might follow and develop, there is also a need to recognize and counter the Eurocentric bias of existing social models of disability. In the Indian context, that requires scholars to look beyond the civil rights battles of the West that underpinned, for example, the independent living movement in the US, and to re-

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focus on the contemporary and historical conditions – socio-economic, cosmological and environmental – that shape the particular experiences of living with different kinds of bodies in South Asia. If disability studies is to be emancipatory as well as intellectually exploratory, it also needs to draw on South Asia-specific struggles – including, but not limited to, those related to colonialism, caste and gender – in order to capture the imaginations of those who have been politically active in them and to highlight how they intersect with disability.

There is a style of argument, even propaganda (for there is usually little genuine engagement with opposing liberal views), that can be seen in many other areas of academia. It amounts to a relatively new ‘progressive’ industry with various fashionable keywords, phrases and ideologies – often not obviously related to disabilities in any serious way – indicating the nature of the beast: progressive, radical, oppression, bourgeois, empowerment, rights, equal opportunities, discrimination, prejudice, citizenship, social justice, socially constructed, Marxism, Post Modernism and Feminism. The overall picture is that disability has become increasingly politicized along politically correct lines to the detriment of society as a whole and, eventually, even to the disabled themselves.

IMPORTANCE OF KNOWING

Disability Studies has offered us critical approaches with which to re-think and re-assess existing research tools and methods in any discipline. Within the discipline of literary and cultural studies, it has become possible to reorient the way we think about disability as a thematic and re-evaluate the way we have traditionally thought about the representation of disability and disabled characters. In addition, theories of disability study have motivated critical ways of studying taken-for-granted forms such as the tragic and the comic. For instance, is the very idea of tragedy ablest because of its use of disabled characters to invoke pity and terror? The inclusion of genres such as deaf poetry has recalibrated our thinking about poetry as primarily oral or written. With the entry of disability aesthetics, there has been a questioning of the very premises that underwrite notions of literary aesthetics thus leading to a kind of *deforming* or literary and cultural texts.

The importance of knowing the disability figures is to integrate the children with special needs and adults more effectively into the community at large. It helps to collect systematic information on disability and the social position of disabled persons and facilitates a provision of services and assists in their reaching out to people with disabilities. It is important as it helps to increase awareness among government organizations and the research community of the limitations and strengths of disability data. Also, it provides some indicators of needs for medical, rehabilitation and welfare services. Knowing the number of children with special needs is a fundamental question in the field of special education. Figures reveal that only a very small percentage of the total disabled population is benefited by the special education programmes. The information about prevalence of various disabilities to

determine the personnel and other resource needs is crucial. Patel et al. (2009)¹ using NSSO 2002 data, observed that locomotor disabilities are the most prevalent type of disabilities affecting of all ages in India. Mental disabilities are the highest in the working age population, whereas visual and hearing disabilities are the highest in the aged. In India, perhaps no population-based study has been conducted at the national level to provide authentic data on the prevalence and incidence of disability. Different prevalence rates for disability are available in India. According to the Census 2001, there are 2.19 thousand people with disabilities in India who constitute 2.13 % of the total population (Census 2001)². Out of the 21,906,769 people with disabilities, 12,605,635 are males and 9,301,134 females and this includes persons with visual, hearing, speech, locomotor and mental disabilities (Census 2001)². In contrast, the National Sample Survey Organization (NSSO) estimated that the number of persons with disabilities in India is 1.8% (49-90 million) of the Indian population (NSSO 2002), that 75% of persons with disabilities live in rural areas, 49% of the disabled population is literate and only 34% are employed (NSSO 2002)³. Knowledge about how children learn, and understanding about what constitutes effective teaching and classroom management has increased considerably over the past decades. Schools and teachers can dramatically influence the extent and quality of learning for all students, *and we know how!* The emphasis must be on success, rather than on failings and shortcomings. To make this possible, a learning environment needs to be created in which all children feel safe and understood, and can reach their potential.

POTENTIAL FOR CONTRIBUTIONS

Most persons with disabilities are barred from leading a dignified life, being profoundly secluded within the home or the walls of institutions. Persons with disabilities are majorly disenfranchised and have poor access to basic services of health, education and social protection offered by the government in India. This nexus of socio-economic and cultural factors contributes to poor estimation on its prevalence thus impacting on their collective strength of demanding and advocating for their rights. Drawing from the research works, it is suggested that research practices that can contribute to disabilities studies can include capacity building of disabled persons’ organizations to become contributing citizens of the country; engaging various stakeholders participation to change the attitudes and offer reasonable accommodation in all spheres of life; and striving for governance reform for better service delivery to develop a receptive and conducive society that is tolerant and humane towards persons with differing abilities.

"The disabled are the ones who are challenged, need to be heard. To be seen not as a disabled/helpless, but as a person who has, and will continue to bloom. To be seen not only as a handicapped but as a well intact human being."

(Robert M. Hensel)⁴

The aesthetic approach brings to light certain positive developments with regard to introducing disability studies in the university curriculum. Firstly, teaching disability through aesthetic method familiarizes students with issues concerning disability in a non-theoretical and uncomplicated manner. For instance, it is much easier to explain the cultural constructions of normality and abnormality by way of demonstrating the same in paintings and sculpture. Secondly, artistic expressions on disability are known to provide a counter-discourse on the ongoing stigmatization, and therefore, they evoke a strong emotional strain for respecting the identity and individuality of the disabled populations. Thirdly, and more importantly, since disability studies has been [wrongly] understood to be the domain of the activists who pose a threat to academic institutions with several demands, introducing the aesthetic approach presents disability studies through non-partisan and apolitical vantage points. Since the discipline is in its nascent stage in the Indian scenario, it seeks to argue that an aesthetic model will play a major role in the institutionalization of disability studies.

OVERVIEW OF EDUCATION FOR DISABLED IN INDIA

It is estimated that the number of children of school-going age who suffer from disabilities may be more than 20 million in India. Despite their social, religious, economic, political and geographical differences, most Indians consider disability as 'phala' of 'karma'. This line of thinking, in which the past, present, and future are attributed to supernatural powers typifies Indian philosophical thought with its belief in 'karma', and is accepted in large part even today. In Indian psyche, the disability is still considered a punishment for sins of previous birth.

In India where education of the non-disabled is a challenge to achieve, the education scenario for the disabled children reflects a rather grim picture. The issues which are crucial for the education of disabled children which need a closure look are the availability special schools, access to schools, trained teachers, availability of educational material for the disabled. The situation of special schools in India is quite appalling. According to the Sixth All India Educational Survey report (NCERT)⁵, of the 6,461 towns and cities, only 334 or 5.1 percent towns and cities have the facility of special schools catering to severe disabilities. In these towns, a total of 630 schools is actually functioning of which 97 admit only boys and 33 are girls and the rest admit both. Of these, some schools may be dedicated exclusively to a particular disability while others cater to needs of children suffering from different types of disability. Categorization of these schools according to their specialization indicates that 215 are for the visually impaired, 290 for hearing impaired, 190 for orthopedical problems, 173 for the mentally challenged and 60 for other locomotive disabilities. The facility of special education is rather skewed. Data shows that of a total number of 586,465 villages in the country only 241 have facilities for special education for the disabled. A further look at the

State-wise distribution of these schools shows that 83 percent of these schools are in the States of Andhra Pradesh, Bihar, Gujarat, Haryana, Kerala, Madhya Pradesh, Maharashtra, Orissa and Union Territory of Andaman and Nicobar Islands. Of the 272 available schools, 55 are for boys, 11 for girls and the rest are for coeducation. Categorization of these schools in terms of their specialization shows that 73 are for the visually challenged, 128 for speech and hearing impaired, 70 are for mentally challenged and 25 caters to various other handicaps. In the absence of adequate number of special schools the other issue, which requires discussion, is of integration of education of the disabled children in mainstream education.

In fact, the Universal Education program envisages to universalize education by educating the disabled children through the mainstream schools. This is possible only if there are adequate numbers of teachers with special training at the primary level. In the primary schools in India, the number of trained teachers is not only inadequate. The teacher training programs which provide disability training emphasize that specialization should be sought for a single type of disability. But this is a very expensive proposition for the Indian situation. So the situation demands that either the training programs should offer multi-disability training or the general teachers training courses are remodeled in a way to equip all the teachers to address the concerns of disabled children. Another critique of the integrated education system is that it is suitable only for children with moderate disabilities. The system is unable to include the children with mental disability. These children are unable to attend the mainstream schools due to stigma and discrimination and also because of their inability to cope with the academic syllabus.

Despite all odds, some progressive steps have been taken in India. In keeping with demands for a more inclusive system of education in India, the government promises to include disabled children in all its educational programmes. In a move to make the educational system more inclusive, the Government has promised to include disabled children in all its educational programmes, including the Sarva Shiksha Abhiyan (SSA), Rashtriya Madhyamik Shiksha Abhiyan (RMSA) and the Integrated Child Development Scheme (ICDS). The education of children with disabilities is offered through a variety of service models ranging from segregation to full inclusion in a mainstream classroom. More than 50,000 children with disability are enrolled in the Integrated Education for Disabled Children, a government-sponsored programme. While the Sarva Shiksha Abhiyan (SSA)⁶ has made a concerted effort to promote the inclusion of children with special needs, the system faces challenges in identifying these children and responding to their needs. Only around 1 per cent of funds under SSA are spent on inclusive education. And, the budget for educating children with mild to moderate disabilities in regular school settings has not increased commensurately since the focus on inclusive education began in the 1980s. A few schools have resource rooms and employ special

education teachers to help retain children with special needs in their system. Sadly, these facilities are found in very few cities. Since there are almost no special schools or special educational services in rural India, integrated education for children with special needs is provided by default in the village schools. The impetus for both integration and inclusion comes largely from a concern for the rights of children and young people with special educational needs. The concept of inclusion has emerged from ideas of providing equal opportunities to all children. Meaningful inclusion cannot be accomplished by special education teachers working alone; it also does not help in having a temporary 'deal', with the regular school teachers to 'take care' of their students. Meaningful inclusion in schools requires that administrators, teachers, and parents not only value diversity but also question the traditional ways we segregated students who are difficult. The goal of full inclusion is placement and instruction of all students regardless of type or severity of disability – in their neighborhood schools, in the regular classroom. With the contribution of NCERT and with the launching of Project Integrated Education of the Disabled (PIED), 1987 with the assistance of UNESCO led to the realization that integrated education was a cost effective approach and that led to an increase in enrolment rate of disabled children in regular schools. The District Primary Education Program (DPEP) and Sarva Shiksha Abhiyan (SSA) have provided further impetus but Inclusive Education has not gone parallel with the accelerated pace / speed of development of educational programs and practices in general. The ground reality is that regular school does not provide full range to resources necessary to deliver a full curriculum for all children, through a combination of class teacher, specialist, semi-specialist, resource teacher consultancy and ancillary staff, as necessary. Moreover, the school does not provide the combination of all three perspectives of inclusion i.e. physical inclusion, social inclusion, and cognitive inclusion.

Children in regular schools do not easily accept children with Special Needs. Therefore, the institutions which claim to be practicing inclusive education are not able to provide total inclusion to all children. So, the most popular is a special institution as they provide services to children with special needs, according to the degree of their impairment and learning needs. The enrollment figures of children with special needs in regular schools are lesser than the enrollment figures in special institutions.

AWARENESS AND NEED OF REHABILITATION

The disabled constitute about the one-tenth population of the world. It is not only inhuman but also uneconomical to discard their economic potentiality and consider them as a burden on the society. Due to the psycho-social barrier, vast productive potential of the country goes unrecognized and therefore, unutilized. As a consequence not only the disabled are subject to traumatic experiences, but also the community suffers a great social cost in terms of potential loss of their contribution. These considerations bring out the necessity to integrate them in the

socioeconomic mainstream of the country. Scholars in various disciplines owe a duty to rouse the social conscience so that a positive approach is adopted.

For a disabled man, a wide variety of factors determines his status in a given society. People, possessing physical defects of one kind or the other, were termed for centuries as cripples. It was only last hundred years or so, they gradually came to be known by the more accepted terms like "Physically Handicapped" or the "Disabled". The emergence of the new terminology is quite significant as it indicates the new approach to the problems of the physically disabled. This new approach was indeed, the result of changing cultural and social values and economic and technical advancement which consequently modified the attitude of the community towards disability. This change was further reinforced by factors such as increasing incidence of disabled population, availability of medical, educational and vocational know-how of rehabilitation, the spread of religious ideas and political ideas like liberty, equality and fraternity and a number of other factors gradually softened the societal attitude towards the miserable plight of the physically disabled. Statesmen, social thinkers, and philanthropists turned their attention towards them and tried to put an end to their misery mainly through charity. Consequently, a number of institutions sprang up to protect and take care of the disabled. Governmental and constitutional measures were taken up by some progressive countries to ameliorate their plight.

The quality of life of the disabled persons in developed and developing countries has been a subject of many scientific studies. It is well known that the disabled persons receive less education and vocational training, and are often unemployed. Although some of them receive the disability benefit, their economic situation is less favorable than that of the able-bodied and thus, their standard of living may be lower. Some of them marry and raise a family.

The problems related to lack of say in their own welfare have been somewhat magnified during the last few decades, but still many of the disabled have no influence on policies and services aimed at them. In the developing country as ours, the problem of rehabilitation of the physically disabled has to be viewed in the total context of the enormous problems that confront our population in general. While extreme poverty, disease and illiteracy handicap the efforts at solving the problems of food, clothing and housing, the one factor which overcomes even the most optimistic planner is the physical enormity of the task facing us in terms of a big population increasing at an uncontrollable fast rate. Any rational endeavor to solve a most difficult situation must be preceded by a scientific evaluation of the extent of the problems and clear and a realistic spelling out of our goals and objectives.

Rehabilitation is an integrated program of interventions that empower individuals with disabilities and chronic health conditions to achieve "personally fulfilling, socially meaningful, and functionally effective interaction" in their daily contexts.⁷

Theodore Millon (1987),⁸ a personality psychologist suggested that changing societal values have led to a rise in psychological disorders. Social instability makes children perceive the world as threatening and unpredictable and thus increase the risk of developing the disorder later in life. The rehabilitation psychologist consistently involves interdisciplinary teamwork as a condition of practice and services within a network of biological, psychological, social, environmental and political considerations in order to achieve optimal rehabilitation goals.

Total rehabilitation means medico-socio-psycho-cultural rehabilitation which makes the disabled man feel that he is in no way inferior to the able-bodied people. A totally rehabilitated man may be expected to be free from the self-isolation phenomenon and is expected to come out of the narrow world of the disabled by breaking the boundary. By using properly his abilities, he is back in the society as a complete human being in all aspects and lives as a useful member of his family as well as the society. Thus, rehabilitation is the most strategic weapon to combat the menace of disability.⁹ There are two perceptions of rehabilitation. One is medical perception which views rehabilitation as assisting all those medical measures which expedite recovery in the physical sense. Whereas according to the other view, rehabilitation means the restoration of the disabled to the fullest physical, mental, social, vocational and economic usefulness of which he or she is capable. In other words, rehabilitation is a goal oriented programme which aims at enabling an impaired person to reach an optimum mental, physical or social functional level in consonance with his current abilities. The rehabilitation process thus involves basically three aspects. These aspects are:

1. Physical rehabilitation or the medical rehabilitation
2. Vocational rehabilitation and
3. Psycho-social integration.

All these aspects are interlinked with each other and equally significant in the rehabilitation process.

Problems affecting the rehabilitation of the disabled in India are likely to be different from those in the other part of the world. They are likely to be different, not only in the magnitude and causative factors, but also in their effects on the disabled person because of the special features of Indian social set-up, social customs, social values and the way of life. Inadequacy and inaccessibility of services add to the problems. Depending upon the level of organisation of the society, application of its organized community resources for the benefit of those in need, the efficiency of the rehabilitation services will vary. In a developing country like ours. It is worthwhile to make a systematic survey of the facilities available at the national level and to delineate the problems encountered by the actual sufferers in obtaining rehabilitative services. Understanding of the psycho-social factors that contribute for the additional burden of suffering will be of importance to organize services in a meaningful manner.

PRESENT SCENARIO ABOUT DISABILITY

The decade of 1990-2000 witnessed intense lobbying and pressure mounted from civil society organizations throughout the country for prevention, protection, and rehabilitation of disabled persons, as it was considered as a rights issue instead of a welfare measure. This pressure culminated into passing of the Persons with Disability (PWD) Act, 1995 in the Indian parliament for providing equal opportunities to disabled persons. Intense lobbying and pressure also resulted in inclusion of questions on disability in the Census 2001, to ascertain the magnitude and types of disability in India. Separate questions on disability were included in the census 2001.

Nowadays, though we have entered a new era of nanotechnology and globalization, the situation has not changed much as yet. In all countries of the world, persons with disabilities are the largest minority group. As a group, they are starved of services and facilities available to the non-disabled and, consequently, are the least nourished, the least healthy, the least educated and the least employed. A major chunk of the member of society still considers them sick, morons, conspirators and idiots. The traditional media also portray them as beggars, robbers, and conspirators. Disabled are portrayed in public through books, magazines, plays, comics, cartoon shows etc. as dangerous, ugly, deformed, monstrous and handicapped. This results in the development of the negative image of disabled in the minds of the public.

All over the world the disabled persons are subjected to isolation, segregation, poverty, deprivation, charity and even pity. The plight of the disabled in India is not different. The immense responsibility for the care of the disabled is generally left to their families and a few institutions managed by voluntary organizations and Government.

Since the disabled, as yet, do not have any economic or political or media power, they tend to be mostly ignored by society. This deliberate and calculated indifference of society is reflected in all facets of the lives of the disabled from cradle to grave. The educational, social, health, transport and residential arrangements made by local, State, Central governments or voluntary organizations frequently fall short of the total demand for them. They are also uncoordinated and irrelevant to the actual needs. The approaches, either out of a profound lack of understanding or sheer callousness, are designed to promote dependence, charity and segregation of the disabled instead of independence, dignity, self-respect and integration. These common practices reinforce the traditional and misguided stereotypes that continue to project people with disabilities as deserving pity, alms, and charity. The prejudices against the disabled and ignorance about their potential get institutionalized and are inevitably reflected in policy making, resource allocation, service provision and the status accorded to them.

CONCLUSION

There are various special programmes run by Government Organizations and Non-Government Organizations for children with special needs. Government policy, legislative actions, schemes and provisions for the disabled give the impression of a state that is committed to human rights and equal opportunities. But the ground reality is quite different. The disabled children continue to be neglected and marginalized, with the onus of care on the family rather than on the community. India needs to shift focus from the medical model of intervention to community rehabilitation of the disabled. There is a need for a holistic approach to this issue. We need to change the education system to make it accessible to all children and prepare the society – the parents, friends and employers to provide support to the disabled children. Although India has a growing disability rights movement and one of the most progressive policy frameworks in the developing world, a lot more needs to be done in the implementation and getting the basic rights. The magnitude of the problem of disability is vast and its impact is severe on the individual, families and community. There are several accepted political goals such as universalization of elementary education, mass literacy programmes, poverty eradication programmes, health for needy people and other developmental programmes. These are aimed at improving the quality of life of people with disabilities.

The magnitude of disability in India is large and brings about the need for developing comprehensive rehabilitation programs for the welfare of disabled millions. The disabled are part of the human family. A chain is only as strong as its weakest link. The weaker links of humanity have to be made strong. We need to be concerned, considered and concrete action. The rehabilitation is not the responsibility of one community, state or country alone anymore. It is a global responsibility. We cannot neglect or ignore the needs and problems of 10% of the human population. They ought to be given the opportunity to lead their lives with dignity. They must earn a living rather than subsist on the mercy of others.

The disabled, the family, the community must cooperate in our plight towards the independence of the disabled. The society, voluntary organization, local, national and international, government at the state and central level must co-operate and collaborate in this noble venture. By this, we can dream of a society where the disabled will have employment, financial security, set up their own family and lead an independent life by using appropriate assistive technology. Here will be no more dissimulation on the basis of disability. The disabled will become contributing and taxpaying citizens with equal status at par with others and be integrated into the mainstream of society. And disability studies play crucial role towards this development by creating awareness and helps in implementing policies for differently abled people.

The fundamental rights of the disabled are no longer be denied or delayed. Life's, health, education, training, employment, entertainment, leisure, marriage, family and such

rights are for everyone to enjoy whether they living in cities, suburbs or rural communities, whether they are born in a wealthy mansion or a filthy hut, in the West or East, North or South.

Disability is not a respecter of persons. It can happen to anyone, anywhere, anytime. It is only wise to be prepared for it before it strikes. We have to redirect our research goals and inventive capabilities to rehabilitation, reconstruction and restoration. And finally, it is concluded that a disabled person can function as well as anybody else provided he/she is given appropriate training alternative techniques and assistive devices. A human mind is a terrible thing to waste, so is the body. Let us maintain it the best way we can. Let us not allow anybody to be imprisoned in his/her body. Liberate the human spirit, restore the human body and finally let us liberate the disabled and open the world for them to this 21st century.

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