

INCLUSION OF PERSONS WITH DISABILITIES: A LONG-AWAITED JOURNEY!

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ABSTRACT

This paper discusses the present scenario of persons with disabilities in West Bengal, India. Even after 70 years of independence, 20 years of the passing of Persons with Disabilities (1995) Act and a few months of the Rights of Persons with Disabilities Act (passed in December 2016), the daily environments of persons with disabilities in the state remain inaccessible. This is despite the fact that in the last two decades of the twentieth century, UNO sponsored multiple initiatives for the empowerment and inclusion of disabilities in the mainstream society that finally culminated in the United Nations Conventions for Rights of Persons with Disabilities (2006). Although disability rights movements that emerged in the late twentieth century within the broader disability discourse have taken a new shape, many issues especially those at the intersection of disability and education remain unaddressed. In this global scenario, the perpetuation of overt and systemic discrimination against persons with disabilities by institutions in the state of West Bengal is a result of lack of empathy and understanding. In this paper, we examine different aspects of inclusivity and the current state of 'mainstreaming efforts' in West Bengal within a broader historical perspective. We emphasise the respective roles of the state, the civil society, and individuals, both with and without disabilities, in this context. Our discussion is primarily based on a field survey, and a critical examination of popular theoretical assumptions regarding persons with disabilities, in the context of West Bengal. Finally, we also present a few case studies, which were recorded during our field-study, to humanise the condition of persons with disabilities in West Bengal. Overall, this article tries to highlight the daily experiences of disabled persons in the state.

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1. Introduction

Inclusion and mainstreaming of persons with disabilities is a significant area in Disability Studies. A remarkable change in the history of disability could be noted from early 1970. The change encompassed many facets of disabled peoples' lives such as education, vocational training, rehabilitation and employment. From 1990s, the legislations proposed inclusion and mainstreaming of disability in different countries. In India, The Rights of Persons with Disabilities Act of 2016, which eventually repealed the Persons with Disability Act of 1995, emphasises on non-discrimination, full and effective participation and inclusion in society, equality of opportunity and raising accessibility in every sphere. But whether the new legislation is going to improve the daily environments of persons with disabilities remains to be seen.

Both the definition of disability and the attitude towards persons with disabilities are changing. But the central question of the problem has remained unaltered. Is it really possible to think that persons with disabilities and persons without disabilities are equal, ignoring the body image and physical appearance?

The article develops in four stages. Firstly, it discusses the definition of disability and its evolution. Next, it focuses on the inclusion process and the role of the state policies for mainstreaming. The discussion on different phases of inclusion in West Bengal follows. Finally, it dwells on a few case studies about discriminatory attitude towards disability based on daily experience of persons with disabilities gathered through personal interview.

2. Methodology

The study, which involves the interplay of both qualitative and quantitative methods, is based on a field survey, and we examine certain well-known theoretical assumptions regarding the daily experiences of the disabled persons. The article embodies interviews of more than twenty-five persons, including different sections of persons with disabilities (such as right activists, teachers, hawkers, and beggar(s), parents of disabled persons and persons without disabilities. The interviews were conducted from March, 2012 to April, 2016. This article attempts to be combine theoretical and empirical research findings on persons with disabilities in the state of West Bengal.

3. Definition of ‘Disability’

There is a lot of debate regarding the definition of disability. The United Nations Convention of Rights for Persons with Disabilities (UNCRPD), 2006 proclaims that disability is an evolving process. There are multiple definitions of disability dependent on a boarder historical context. In general, there are four models of disability, viz., the Charity Model, the Medical Model, the Social Model and the Human Rights Model. Each model provides a different a certain kind of definition of disability.

In developed countries, there is a clear distinction between impairment, handicap and disability. P. Donald and P. Headly (1989) explain different positions about disabilities:

Impairment: any loss of physiological or psychological normality or anatomical structure or function.

Handicap: a disadvantage for a given individual resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and socio-cultural factors) for the individual.

Disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being.¹

Historically, disability is usually defined based on a few physical traits. Primarily, medical science had defined disability based on some particular parameters. Thereafter, a lot of further definitions have come forward from the sociologists. It has been seen that the definitions have been continuously modified over time. And going by the trends, newer changes are awaiting in the future.

Disability is situated within a larger social context, while impairment is a biological condition. Lennard Davis has succulently described the relationship between disability and impairment as follows: ‘Disability is not so much the lack of a sense or the presence of a physical or mental impairment as it is the reception and construction of that difference.... Impairment is a physical face but disability is a social construction.’² For example, the lack of mobility is impairment, but an environment without ramps turns that impairment into a disability

¹ P. Donald, & P. Headly (ed.) (1989), *Disablement in the Community*, New York: Oxford Medical Publication, p. 5.

² Lennard Davis, (2006), ‘Constructing Normalcy: the Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century’ in Lennard J. Davis; *The Disability Studies Reader*, New York: Routledge, Second Edition, p. 3.

..... A disability must be socially constructed.³ Mike Oliver (1990, 1996) coined the term ‘social creationist’ to describe the British Social Model approach,⁴ distinguishing it from both the biological determinism of the medical model and the less materialist approaches associated with social constructionist ideas.⁵

Tom Shakespeare (2014) argued that the Social Model also replaces a traditional deficit approach with a social oppression understanding. It was and remains very liberating for the disabled individuals. Suddenly, people were able to understand that disability was a social lacuna. The people need not change; the society needs to change. They did not have to feel sorry for themselves; rather they could be angry. They were empowered to mobilise for equal citizenship. Rather than a demeaning reliance on charity, disabled activists could now demand their rights-based environment. They further interpret disability within a multicultural context as a manifestation of the diversity of the human condition and not as an undesired biological ailment to be cured and corrected through medical intervention. Disability is, thus, understood as a culturally constructed phenomenon rather than a biological one.

UNCRPD defines disability as follows: ‘Disability results from the interaction between persons with impairments and attitudinal and environment barriers that hinder their full and

³ Ibid

⁴ In the world of academia, the British social model opened up new lines of enquiry. Whereas the medical sociology of disability had traditionally investigated issues such as individual adjustment to impairment, and explored the consequences of impairment for identity, the social model inspired researches in the new field of disability studies to turn their attention to topics such as discrimination, the relationship between disability and industrial capitalism or the varying cultural representations of people with impairment. Tom Shakespeare, (2014) *Disability Rights and Wrongs Revisited*, New York: Routledge, p. 13

⁵ Mike Oliver (2013), ‘The social model of disability: Thirty years on’, *Disability & Society* Vol. 28, Issue 7, pp. 1024-1026

effective participation in society on an equal basis with others’ and more emphasis on ‘Persons with Disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’⁶

4. State policy and inclusion

Post Second World War, different parts of Europe developed a consciousness and concern for disabilities. As a result, many states implemented quite a few policies and reform programmes for the welfare of the disabled community. These changes are also seen in contemporary India, but in a very laid-back manner. In the first four decades after independence, Indian state treated persons with disabilities as a weaker section of the society similar to schedule caste and tribe.⁷ India, however, never had a definite and consolidated approach to the problem of disability for the reason that disabled community never emerged as vote-banks unlike other marginalised groups.

⁶ The Convention notes that disability is an evolving concept and results from the interaction between a person’s impairment and obstacles such as physical barriers and prevailing attitudes that prevent their participation in society. UNCRPD,2006, www.un.org, (accessed on 1st June, 2012)

⁷ The first three 5-year plans treated disabled people as constituting the weaker section of the society. Their inclusion was limited within the boundaries of welfare. For further details refer to www.planingcommission.nic.in (accessed on 13th January, 2013).

From the 1980s, the Government of India created a few policies such as 3% reservation of education and group C or D category job for the welfare of the disabled people.⁸ Over time, due to pressure from the society, there have been meaningful responses from the authorities. The PWD Act of 1995 is one such meaningful response. It proposed equal opportunities, protection of rights and full participation in every sphere of life. However, the implementation of the Act was insufficient in West Bengal due to lack of proper consciousness, want for socioeconomic support and many others odd administrative reasons. Post 1995, the initiative for implementing the welfare schemes somewhat shifted to Non-government organisations (NGOs). The NGOs had limited reach and, thus, the developmental work was also inconsistent. The progress of the community as a single entity was not possible. The rural areas were the worst sufferers as most of the NGOs could only penetrate into the urban areas. As more persons with disabilities live in rural areas, the purpose of extending benefits and assistance to the disabled people was defeated. Recently, the Rights of Persons with Disabilities Act (2016) opened up new lines for mainstreaming inclusion of disabilities.

5. Different stages of inclusion

In West Bengal, the history of inclusion and mainstreaming process has three overarching concerns. Firstly, there is a stark division between persons with and without disabilities. Secondly, the malpractice to wrongfully acquire disabled credentials to enjoy the advantages

⁸ Indira Gandhi (1981), 'Sympathy for Disabled Persons', Ministry of Information and Broadcasting, Prime Minister Speaks', cited in Mani (1988), *The Physically Handicapped in India: Policy and Programme*, Delhi: Ashish Publishing House, p. 134

provided by the government, and finally, there are continuous endeavours of the persons with disabilities to gain true appreciation in the society.

Concerning the first point, there has always been an invisible borderline between the two communities. Dwelling deep into the consciousness of a contemporary person with disability, there is apprehension and fear in daily life. On the other hand, their associations encourage them to break free. Unfortunately, their acceptance has always been difficult for the mainstream society as one of their own and persons with disabilities always feel themselves as the 'other'. Even after fifty years of the 'stigma' theory by American psychologist E. Goffman, the worlds of people with and without disabilities are not accepting each other.⁹ The people without disabilities more often than not are ignorant of their disabled counterparts; on the other hand disability is used as a weapon to gain advantages from the society. Historically, people without disabilities ignore that issue. I think this issue has tremendous relevance and, in modern times, requires further research and importance.

⁹ According to Goffman, stigma is to protect their identities when they depart from approved standards of behaviour or appearance, people manage impressions of themselves – mainly through concealment. He showed three form of stigma- firstly, Overt or external deformations, such as scars, physical manifestations of anorexia nervosa, leprosy (leprosy stigma), or of a physical disability or social disability, such as obesity. Secondly, Deviations in personal traits, including dropping out of school, working a low wage job, single parenthood, bankruptcy, unemployment, welfare dependency, adultery, mental disorder, teenage pregnancy, drug addiction, alcoholism, and criminal background are stigmatized in this way and finally 'Tribal stigmas' are traits (imagined or real) of ethnic group, nationality, or of religion that is deemed to be a deviation from the prevailing normative ethnicity, nationality or religion. E. Goffman (1963), *Stigma: Notes on the Management of Spoiled Identity*, New York: Prentice-Hall.

In the second stage, the society reacted to the problem and started developing policies and reform programmes to bring the persons with disabilities into mainstream inclusive society. Initially these steps were driven by a sense of humanity and service but gradually the outlook began to change. Promotion of education, setting up of special residential educational institutions and different vocational training programmes and proper rehabilitation policies saw they progress from strength to strength.¹⁰ The results reflected not only economic independence on the part of the disabled people but also self-respect and dignity.

The consciousness about rights also came into play in the light of education. And in response to the ages of discrimination, ignorance, isolation and neglect, a movement started to claim equal citizenship and full participation in the society and opportunities for development. Though a lot of help and involvement in the movement came from people without disabilities, the primary initiative and work was completely done from within the community. It is safe to say that the persons with disabilities themselves tried to improve their condition and advance.¹¹

But these efforts are not unanimously fruitful. Compiled data from surveys reflect that most of the persons with disabilities have been reluctant to move up to inclusive or mainstream society and world of people without disabilities. The mentality of the so-called ‘normal people’

¹⁰ There has been so many residential educational institution since last decade of the Nineteenth Century such as *Calcutta Deaf and Dumb School* (1893), *Calcutta Blind School* (1894), *Light House for the Blind* (1941), *Ramakrishna Mission Blind Boys Academy* (1955) and *Ananda Bhawan Special Education & vocational Training Centre* (1997), where numbers of People with different kind of disabilities get education and vocational training.

¹¹ Bubai Bag. 2011. “Paschim Bangyer Pratibandhokotajukto Manushder Artha-samajik Ruparekha: 1947-1995.” M.phil thesis. Jadavpur University, Kolkata. p 73

is also responsible for that. In most of the cases, persons with disabilities and their family are concerned with advantages and benefits, rather than their rights and duties to the societies.¹² . For example, beggars with disability always ask ‘Give the money in the name of Gods’ and ‘if you give the money to me, god will bless you’,¹³ which is based upon charitable form and divinity of the persons with disabilities. As result, a disabled person always shows be deficient in of normalcy. Due to this abnormality, persons with disabilities are dissimilar from many others marginal groups.

6. Case Study of West Bengal

In this part, I will point out the present picture of disability within the context of socioeconomic, political and cultural historical development, since independence. These pictures will provide a reasonable idea of the attitude of the civil society towards disability over the first and second decades of the present century. Here, we discuss a few case studies which were conducted during survey period. These pictures also help us understand the daily life and living experience of persons with disabilities in West Bengal.

I. In 2013, an incident took place in the district of Nadia, which is about 80 kms away from Kolkata. The Head Master of a government-aided primary school denied admission to a child with special needs. The Head of the institution told that the parents of the other children might not be too pleased with that. He also suggested that there are many special residential schools meant for such children and the child should be admitted there. This incident clearly reflects that

¹² Bubai Bag. 2016. “Paschim Bangyer Pratibandhi Manush: Prantikotar Nanadik (1947-2012)”, Ph.D. thesis. Jadavpur University, Kolkata. p. 231

¹³ Interview with Sk. Mujibar Alam, Beggar with Disability, Burdwan (15th December, 2014).

the concept of 'inclusive education' (which is an integral part of Right to Education Act, 2009) has brought no change in the outlook in among people inhabiting the rural parts of West Bengal.

II. A girl with a locomotor disability cleared the medical entrance examination in 2012 but was denied admission by the principal of a government medical college citing the reason that she would be unable to cope with the physical challenges of the training, though many accomplished practitioners held a different view on the matter. Here again we see that contrary to the idea proposed by the Persons with Disability Act 1995 that a disabled person should be allowed full participation and protection of rights in any activity which he/she thinks he/she is fit to go for, the unfortunate candidate had to bear the brunt of the social problem.

III. A Person with deafness had gone to the district general hospital for treatment. He used sign language to communicate with the doctor, who, being unable to understand the language, could not provide the appropriate treatment to him. This resulted in the worsening of the patient's condition. Here again we see that the physician was reluctant to use an interpreter to help. The mistreatment of the patient reflects the negative attitude of the society towards the disabled.

IV. Amal Mondal, a person with Blindness (100%) was recruited on his merit in a government-aided school through the School Service Commission examination held in 2007. When he went to join his school, he got stigmatised as a 'Blind' by one of his own colleagues who expressed her dissatisfaction on the new teacher's appointment. This incident indicates the mentality of a certain specific class towards disability.

V. Rafiqul Islam (lost his both lower limbs in an accident at the age of 10) is a resident of Amta Block in the district of Howrah. He is unable to avail public transport with ease due the disability. He was standing at a bus stop on 25th March, 2014; the incoming buses noticing him

sped past and parked at a distant location, which was not possible for him to reach. The conductor of the bus reasoned that he being a disabled person wouldn't be charged any fare but would occupy a precious seat. This kind of insult affected poor Rafiqul and he subsequently made himself aloof from social gatherings. It should be noted that buses and trains, which are the commonest modes of transport, are still devoid of disabled friendly facilities.

VI. Dinabondhu Banerjee of Bankura district came out with flying colours in School Service Commission examination and got appointed as an Assistant Teacher in a government-aided school. Dinabondhu is a person with visual impairment. After reaching his goal, he was looking to settle down in life. But his repeated advertising in matrimonial sites in all leading dailies yielded no result. His accomplishments as an individual were demeaned and he was judged by each prospective bride only on his physical traits. Like family, marriage in itself is a huge institution. But entry to that institution is restricted for disabled persons. This restriction is based on the popular misconception that a child born out of wedlock of a disabled person inherits his or her disability. The situation of disabled women is worse than that of men in this respect. Every time the news of marriage of a disabled person is announced, a popular question pops: 'is the partner also disabled? Or 'are both same?' This thought reflects the general outlook of the society towards disability.

VII. In recent times, it is seen that most social parties prefer buffet arrangements for food. A person with locomotor disabilities or a person with visual impairment faces a lot of challenges to enjoy food in this kind of understanding. This highlights his/her disability amongst the gathering. Moreover, if a disabled person enters a buffet s/he becomes subject to instant sympathy from others. This unwelcome sympathy makes him/her feel less significant and neglected.

The case studies concentrated on different kinds of disabilities. However, though their forms of disabilities are different, but the social outlook is almost similar. Moreover, the body image of physical disability transcends wealth, education and social status and becomes the most important factor in determining the social attitude towards a person. Finally, I must mention that people with mental illness are the worst affected group. The people with cerebral palsy, autism and multiple disabilities are marginalised even within the disabled community.¹⁴

7. Conclusion

Disabled people encounter a variety of incidents in their lives. The so-called ‘able-bodied’ or ‘normal’ people overlook these problems or ignore them by labelling them as inconsequential. From this perspective, I would like to say that there has always been a clear prejudice against persons with disabilities in the history of West Bengal. These problems have pushed disabled people into becoming a marginal social group and, thus, their history becomes included in the history of marginality.

¹⁴ Bubai Bag, (2016), *op.cit*