



The Fifth World

Dr. Asish Kumar Kundu



Lecture by **Dr. Asish Kumar Kundu**,
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My journey as a doctor for the last forty years has been a little unusual. While studying MBBS in Calcutta I was involved in students' movements and various social service activities. During the seventies I was also a member of the editorial board of Bikhshan, a popular magazine of the students and youth. After completing MBBS I took a rucksack and started a tour of the country to decide where to settle down and work for the poor. I reached Dalli Rajhara in 1981 and met Shankar Guha Neogi and started a health programme there along with Dr Binayak Sen – “Swasthya ke liye sangharsh karo.” In 1982 we started a dispensary and in 1983 we had our own hospital built by the workers funds and toil. Shaheed Hospital as it is called is functioning very well. In 1987 I came back to Calcutta and worked for seven years at the All India Institute of Hygiene and Public Health in epidemiological research and teaching. In the meantime I started studying again and did a Diploma in Child Health. During this period I worked as a pediatrician in a night shelter run by Missionaries of Charity for about a year. Later I worked for two years in the Sonagachi project run by Dr Smarajit Jana. Next I completed MD in Physical Medicine and Rehabilitation and joined the National Institute for the Orthopaedically Handicapped (NIOH), now known as National Institute for Locomotor Disability (NILD) as Assistant Director. I resigned after four years and from then on I am on my own. In sum it has been a very enriching experience for me.

India is traditionally known as a third world country. It is also generally believed that a third world country means a poor country though strictly speaking that is not true.

A few friends of mine have formed a group known as 'Fourth World International.' They claim that within the Third World there is a Fourth World which is often overlooked. The term fourth world was first used to the best of my knowledge as the title of a book "Fourth World Dynamics" edited by Nirmal Sengupta in the late seventies. Its theoretical premise was Jharkhand as an internal colony within a third world country. Later it was used by Dr MP Parameswaran in the All India People's Science Congress in 1998. Later in 2003 he was expelled from CPI (M) in all probability due to his concept of the fourth world.

When a foreigner comes to visit India and goes to visit the Taj Mahal and the Ghats of Varanasi, Rajasthan and the Backwaters of Kerala he misses the Fourth World – slums of tea garden workers, sex workers of Sonagachi, daily wage earners and tribals in general in Jharkhand, Chhattisgarh and other regions. Yes, there is a Fourth World within the Third World.

My contention is that within the Third and the Fourth World there is a Fifth World: the world of disability. Unlike those in the west most people with disabilities in India and their families are focussed on survival in the backdrop of deep poverty. India's disability rights movement however mainly comprises of middle class activists who generally mirror the goals of the disability rights movement in the western countries. Disability in India is affected by other social divisions such as class, gender and caste. Statistics illustrate that in India, women with disabilities are more marginalized than their male counterparts. It is sad but true that Indian feminism has generally ignored the conditions of women with disabilities.

Causes and Forms of Disability

Disability may be present at birth or may present itself later in life and there are many reasons - sometimes complex - which may give rise to the disability. Some of them are enumerated below.

1. **Congenital & Hereditary.** Duchenne muscular dystrophy is one example where faulty genes from parents give rise to disease in the

offspring but it is almost exclusively restricted to males. The child is normal at birth, but in a year or so develops weakness in his muscles. By the time he is around ten he is unable to walk. He dies by the age of twenty.

2. **Infection in the Womb.** A group of infections known as TORCH and syphilis were notorious for causing multiple disabilities in the unborn child. Fortunately these are uncommon now with the advent of immunizations and better anti natal care. Drugs taken during pregnancy can also cause birth defects of which thalidomide is a notorious example.
3. **Premature Birth & Birth Trauma.** One of the most important causes of disability is cerebral palsy and its incidence has not come down over the last five decades.
4. **Infections.** Some infections like tuberculosis of the spine or meninges can cause permanent disability.
5. **Autoimmune Diseases.** Autoimmune diseases like rheumatoid arthritis, multiple sclerosis can cause permanent disability.
6. **Injury.** This needs special mention. With the advent of high speed roads, spinal cord injury and head injuries are becoming the major causes of disability in India. A person with an injury in the lower spine becomes

wheelchair bound and has bowel and bladder problems. An injury to the cervical spine means either death or losing power in both arms and legs. Most of them need a catheter to be introduced to evacuate the bladder four to five times a day either by self if s/he has power in her/his hands or with the help of others.

7. **Old Age.** Over the last four decades life expectancy has increased manifolds and it has given rise to multiple forms of disability. Loss of hearing, loss of eyesight, loss of balance and so on. These people need constant support care for survival.
8. **Diseases.** Diseases like cerebral stroke, cerebral ataxia, Parkinsonism mean that an afflicted person cannot function without support.
9. **Environmental Causes.** I would not elaborate on this. Here it will suffice to say that environmental pollutants like chromium, cadmium, mercury and radiation do cause the most severe types of disabilities and death.
10. **Natural Calamities.** Earthquakes cause hundreds of head injuries and other disabilities.
11. **War and LIC.** The largest number of disabilities in the shortest period of time occurs during war. In fact the subject “Physical Medicine and

Rehabilitation” developed to deal with the disabilities caused by Second World War. After a war is over it is often customary to leave behind land mines by the retreating parties. Such wars are mostly low intensity conflicts. More limbs have been lost due to landmines than any other cause. In our cities we often read about rag picker children injured by crude bombs left behind in the waste bins.

12. **Idiopathic.** We are not sure of many of the causes of disability. But the people affected suffer more so because of the discrepant attitudes of the people surrounding them.

Visualizing the Problem

You have a disfigured body or face and people will stare at you and say “bechara.”

Close your eyes for five minutes in a bus stop near Sealdah Station and you will know what a blind man feels. There are sounds all around. You want to cross the road or catch a bus. As a blind and single you wait and wait till a helping hand guides you.

You have lost an arm and the prosthesis you get from the government is

crude and hardly functional. I have often seen a disabled person keep this prosthesis hanging from a nail in the wall as a sort of souvenir. Modern technology has given beautiful prosthesis which is almost as functional as a normal arm. But that is beyond your reach. Your both legs are paralyzed and you move around in a wheelchair. You want to go to the post office, the bank or to the police station. You can't. In fact you can't even reach, if say you live in Salt Lake, the nearby Eastern Zonal Cultural Centre hall.

You cannot hear and you are crossing a road. A car honks. The driver brakes and shouts innumerable foul abuses at you. Some people will look at you and say it is “karma” (past sins). Prejudice against the disabled is so widespread in India that you will be shunned everywhere. Is there an employer who is benevolent enough to build a ramp for one or two employees with disability?

There are various ugly forms of discriminatory practices seen in the community towards children with disability. These are categorized as denial of disability, physical restraints, social boycott, denial of property

rights, decreased marital life prospects due to presence of a disabled member in the family, or sexuality problem with a person with disability.

Women with disabilities face double discrimination due to traditional gender roles and expectations. Disability locates the individual in a compromised position not only as a function of biology but also as a product of a complex interaction amongst the non-biological factors like gender, caste, clan, neighborhood, the nature of kinship and family structure. Elderly women with disabilities are more vulnerable. Disabled women in rural (even urban) India except in airports and 5 star hotels have no access to disabled friendly toilets. A large number of women are forced to defecate in the open either in the early hours of dawn or after dark which increases their vulnerability to harassment, violence, and sexual abuse.

Accessibility issues relate to education, health services, employment opportunities, transportation, and social and political rights. A recent study by NIMHANS, (National Institute of Mental Health and Neurosciences) Bengaluru of ten mental asylums having large

concentration of women inmates revealed that family members were admitting women to mental asylums in order to grab their land and property. Further, maternal health care services designed to address the needs of able bodied women may lack the flexibility and responsiveness to meet the special maternity care needs of women with disability.

Types of Disability

Persons with disabilities (Equal opportunities, Protection of Rights and Full Participation) Act 1995 defines disability as:

1. Blindness
2. Low Vision
3. Leprosy Cured
4. Hearing Impairment
5. Locomotor Disability
6. Mental Retardation
7. Mental Illness



Magnitude of the Problem

According to the Census 2011, the population of India is 121.05 crores of which 2.68 crores are disabled. The same Census tells us that of the 62.32 crore male population 1.86 crore males are disabled, and of 58.76 crores female population 0.82 crore persons are disabled. Of the total disabled population, 1.5 crore people live in rural areas and 1.18 crore people live in urban areas. Disability rights activists however claim that the figure is much higher. World Bank data suggests that the number of persons with disabilities is between 4 to 8 crores. Whatever the difference between these figures, it is accepted that India has one of the highest number of people with disabilities.

In short, 2.21 per cent of Indians are disabled of which 2.41 per cent are males and 2.01 per cent are females. Of these 20.3 per cent have disability of movement or as we call it locomotor disability. Another 7.9 percent have multiple disabilities of which locomotor disability is a component. After I go through some more relevant data, the rest of this talk will be restricted to the discussion to locomotor disability, as this is my field of work.

The Indian Socio Economic Scenario

If we look at the age group distribution of persons with disability it has been found that 1.82 per cent is between 10 to 19 years, 1.97 per cent is between 20 to 29 years, 2.09 per cent is between 30 to 39 years and the highest percentage of disabled are in the older age group (60 and above). Of the disabled persons (7 years or above) 41 per cent are illiterate. Among males illiteracy is 32.7 per cent and among females it is 51.6 percent. At the all India level 36 per cent of the disabled are working. About 47 per cent of the disabled male population are working (employed or self-employed), while only 23 per cent of the disabled female population work (employed or self-employed).

We have failed to prioritize the problems of persons with disability in India. The reason is simple. We have not been able to minimize the sufferings of the majority – workers, peasants, the tribal population, and the dalits, and I am talking here of able bodied persons. Then, what can be done about the disabled? When the Fourth World is ignored who will bother about the Fifth World except for giving high sounding lip service? It is easy to reserve two seats for the handicapped in a public vehicle. But when people are hanging from the

door handle in a crowded bus how will a disabled get in? When there are so many able bodied unemployed who will employ a person with disability? Of course there are rules. Persons with Disabilities Act ensures certain rights and privileges for the disabled. But like so many other rights in this country these are hardly enforced. And, more importantly, there are unique problems in the field of disability. Let me illustrate some.

Once in a medical camp in the Sundarbans, I was approached by a young robust person who did not have his right great toe and the second great toe was deformed. It seems he was attacked by a crocodile while fishing in the river. He managed to save himself but his great toe was gone. I understood his situation and even before he presented his problem I advised him to wear slippers with a back-strap similar to what I was wearing at the time. He asked me the price of this particular brand of slipper and I said, around Rs 250. He smiled and said he could never afford it. That's poverty for you. In his life's priorities a 250 Rupee chappal was the last rung in the ladder. When the NGO I was working with offered to buy the chappal for him, he declared that I had not understood his problem. Walking barefoot was not an issue, he said. Going fishing he had to

traverse the river bed full will sticky slippery clayey soil. You needed to bend your great toe in the mud to get a foothold. How could he do that? I had no answer.

It is not simply a question of giving a person with disability a means to live, but also giving the satisfaction of living a fulfilling life. Let me tell you another story.

While I was working in SSKM Hospital a tall dangling man came with his wife and four kids. He was from Murshidabad and his profession was smuggling goods from Nepal and selling them in India. While crossing the border one day he was badly beaten up by the police. He had a fracture in his cervical spine and became a quadriplegic which means he lost muscle power in all four limbs. Over time he recovered quite a lot. He could walk or rather limped with two sticks but had bowel and bladder problem. I often advised him to start a pan-biri shop in his village. I said that “You are no longer in a position to play hide and seek with the police.” But he insisted that in his village there would be no income from a pan-biri shop. Finally one day he presented me with a pen made in China. Stunned I asked, “Have you started smuggling again? How do you run from the police? Why do you do it?” He said, “Now that I am crippled police are

sympathetic and actually help me. In the train I sit near the toilet and rush in whenever I need to. Why do I do it? You see sir, when I sit by the window in a train and air rushes in blowing in my face I feel happy. It is then and only then I feel that I have got back my old life.”

The problems that persons with disability have to contend with include establishing relationships also. They have greater anxiety, complexities, and defensiveness, and they suffer from helplessness due to the inability to control the environment.

What are their Priorities?

Studies?

Health Care?

Independence?

Occupation?

Marriage and Family?

People with disability want from life exactly what people without disability want, such as, happiness, meaningful occupation, fulfilling relationships,

independence, being believed in and being accepted by others. They have difficulty in attaining these goals due to prejudice, lack of skills, physical-social-cultural barriers, and economic failures. The essential psychological needs of all humans are the “need to belong”, “need to be valued”, “need to feel that we are good at something”, and the “need to have a secure future.” All these primary needs are denied to people with disability.

Facilities Available to Persons with Disability

Different governments at different periods have introduced different schemes for the disabled. Some of the more important facilities are enumerated below.

1. Income tax deduction – both for the disabled and his guardian.
2. Exemption from professional tax.
3. Scholarship for those participating in post matric/professional/ technical courses.
Scholarship is available from class 9 onwards for children with autism/cerebral palsy/mental retardation and multiple disabilities.
4. Job reservation of 3% in government establishments.
5. Easier loan facilities.

6. Disability pension schemes.
7. Assistance to Disabled Persons for Purchase /Fitting of Aids and Appliances (ADIB Scheme).
8. Railway and airfare concessions.

These facilities are available to persons who have a “disability certificate”, which is issued to only those who have 40% disability. If you look closely at the benefits, these are not meant for the marginalized people with disabilities who form the bulk.

An Interesting Indicator

The 2001 Census showed that only 47.42 per cent of the persons with disability have been issued disability certificates. The 2011 Census showed that only 39.28 per cent of those disabled have been issued disability certificates. The figure has actually declined. It is not that certificates are not being issued. But the rate at which certificates are issued is slower than the rate at which disability is occurring.

My Function as a Rehabilitation Specialist

Rehabilitation is defined as “a set of measures that assist individuals, who experience or likely to experience disability, to achieve and maintain optimal functioning in interaction with their environment.” (WHO 2011) As a rehabilitation specialist I work with a team of occupational therapists, physiotherapists, orthotist-prosthetists, psychotherapists, and so on. My job is to improve the functional abilities of a person with disabilities – improve his gait and balance, improve his hand function, to make him independent as far as possible. I also make it a point to send one of my team members to visit his/her home and give suggestions to make it barrier free. I can make the person aware of the rights and privileges of the disabled and ask him to get a handicapped certificate. This is all I can do and nothing more.

The problem is not how to wipe out the differences but how to unite with the differences intact. - **Rabindranath Tagore**

(I am grateful to Dilip Hota and Chanchala Samajdar for their inputs)

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Late Krishna Bhattacharya
Distinguished Teacher of Education,
West Bengal Education Service



Suchandra Dutta, 24 Parganas (South)
Activist, Working for Disability Rights Group



Sarada Kalyan Bhandar, Medinipur, Working
for Women's (Particularly Girl Child) Education



Bharati Chowdhury Memorial Award by
Avantika Sanyal, Educationist

Fifth Krishna Memorial Awards for Women Educationists, Students and Care givers were conferred on

a) Suchandra Dutta, Activist b) Sarada Kalyan Bhandar, Medinipur and c) Avantika Sanyal, Educationist

By **V. Ramaswamy**, Eminent Social Activist

on

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