# DISABILITY AS A SOCIAL CONSTRUCT: DEHUMANISATION OF THE DISABLED AS SEEN THROUGH INSTITUTIONALISATION IN SUSAN NUSSBAUM'S *GOOD KINGS, BAD KINGS*

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## Abstract

*The paper attempts to point out that 'Disability' is a social construct. The contemporary society ignores pities, patronises, objectifies and fetishizes the impaired which ultimately leaves them disabled. The paper will move on to explicate the concept of institutionalisation and the fear of institutionalisation. It will also touch upon the various ways in which the disabled can be empowered in the contemporary social scenario.*

Susan Nussbaum's novel *Good Kings, Bad Kings* published in 2013 has won the Pen/Bellwether Award for the Socially Engaged Fiction. The work invites the reader into the lives of the 'patients' and staff of the Illinois Learning and Life Skills Centre or ILLC, a fictional state run nursing facility for the Disabled. Told in alternating perspectives of the varied characters, the novel elucidates how failure of social support for people with disabilities result in inadequate rehabilitation, poor protection from physical, sexual and emotional abuse, inadequate personal and medical care, unemployment, inadequate training and education, minimal opportunities for social learning and interaction and exclusion from participation in major aspects of life in the contemporary social scenario. "The term disability hints at something missing fiscally, physically, mentally or legally" (Goodley 1). The disabled are the largest minority group in an already crowded theatre of multiculturalism. The objective of the paper is to elucidate how the needs of the disabled are not accounted for in the contemporary society.

Dan Goodley points out that the, "Disabled people are more likely to be victims of rape and violence, less likely to receive legal protection, more likely to be excluded from mass education, be underrepresented in politics of power and more reliant in state benefits or charity" (2).Joanne Madsen, one of the disabled characters of the novel is a staff at ILLC. She explains the reaction of her family and the society to her quadriplegia,

> My family has never seemed to progress beyond the denial stage as regards my quadriplegia. There is such a thing as job discrimination. People will see me coming through the door, wheelchair awhir, and momentarily freeze. Then they nervously reach out to shake my gimpy hand and smile enthusiastically while they feed my resume to the shredder. (8)

Goodley purports that the disabled are often ignored, pitied, patronised, objectified and fetishized, their presence raises questions about the "right to die" and "assisted suicide" (2). They do not enjoy equitable access to human, economic and social capital resources. Mia Oviedo, a patient at ILLC suffers from blindness and cerebral palsy and considers herself as 'invisible' within the society; "Not that invisibility is hard to achieve when you're crip. We're minor characters in someone else's story" (104). A victim of physical abuse by her father and later by her houseparent at ILLC, the reason for Mia's desire to be invisible is not her impairment but negligence of her wellbeing by the society which thereby makes her disabled. Sociologist, Tom Shakespeare believes that it is necessary for one to understand the difference between disability and impairment.

Disabled People's International lays down the difference between the two; Impairment is the functional limitation within the individual caused by physical, mental and sensory impairment. Disability on the other hand is a label that inaugurates consignment to an identity category, which signifies disadvantage and oppression and results in the total invisibility of the disabled individual. In the novel, the crippled character Joanne Madsen points out that the board of ILLC often struggles with the terms 'disability' and 'impairment' while they refer to their patients. Sometimes they use both the terms simultaneously while the other times they resort to saying either of the terms. "They personally prefer using "handicapped", but they realize there are some new-fangled notions out there about saying "disability", so they're covering their bases" (105).

Jenny Morris in her work *Pride and Prejudice* explicates how the disabled are often referred to as the 'dependent people'. A disabled person's reliance on a barrier free environment, appropriate technology and personal assistance is translated into helplessness and subordination by the contemporary society. In *Good Kings, Bad Kings,* Joanne Madsen says, "I'm just worried they'll [her boyfriend's family] think I'm an "invalid", or poor childbearing material, or the worst imaginable choice for their son, brother et cetera." (270). Hence, "Many disabled people consider themselves victims of this ideology of independence" (Morris 91). The novel also emphasises the perspective of Yessenia Lopez another victim of the ideology; "Everybody looks at me and say, "Oh that girl's in a wheelchair, she can't do nothing"… Even Tia Nene [her grandmother] who loved me with all her might thought deep down that poor Yessie wouldn't ever be able to do a damn thing for herself" (139). Those who are born with, or acquire the type of disability which makes the routine activities of daily life difficult or impossible without help are measured against these standards of independence, and if they are found wanting, then they're categorised as dependent either within residential care or within families.

Even in the 21st century, sexual health and sex education is not equally or accurately provided to the disabled individuals leaving them at higher risk to be victimised sexually and at risk for sexual diseases. In the novel, Mia Oviedo, 11, is sexually abused by her houseparent, Jerry which leaves her physically and mentally shattered. Young Mia suffered from insomnia, fatigue and bleeding as a result of being raped but was scared to report the crime. "You see him like a big bird holding on his claws. I don't feel so good. My coochie hurt real bad. I never telling… he say I better not say anything and put something big in my mouth" (66). Nussbaum while presenting Mia's case by extension hints at how, many disabled like Mia are in the oblivion regarding sexual health. This is because, the Disabled people are often infantilised, constructed as helpless and viewed as asexual. However, this violates the norms and standards put forth in the paper entitled Accessibility and Development by the U.N. published in 2013. According to the U.N the state should take appropriate measures to ensure that people with disability has the freedom to seek, receive and impart information on an equal basis with others (Article 21).

Morris purports the ways in which the concept of institutionalisation torments the disabled. The disability movement throughout the industrialised world has seen the struggle against residential care as one of the most important parts of the fight for human rights. Institutionalisation is the experience of powerlessness which can grossly multiply the effects of the physical limitations of a person. Joanne Madsen points out that, ILLC "locks up young people" (7). "It's just a place they put disabled kids that struggling parents and the state don't know what to do with. Inside, it smells sounds, and looks like your standard-issue nursing home. Same old wolf but in a lamb outfit" (11).The response of the patients at ILLC to institutionalisation reiterates the argument raised by The Union for Physically Impaired against Segregation, that the, the residential institutions for the impaired are the "ultimate human scrap-heaps of this society". For the vast majority who are institutionalised there is still no alternative, no appeal, no remission of sentence for good behaviour, no escape except the escape from life itself.

"Loss of liberty, social stigma, loss of autonomy, depersonalisation and low material standards are the five findings common to life experienced in a wide range of institutions" (Morris 79).Many people who are institutionalised are made to believe that their lives are not worth living because of their physical appearance and the way their bodies behaved. Most often the patients are neglected are not given the help and assistance they require. Out of the eighty kids at ILLC, there have been thirty-two full hospital admissions in a seven-month period. Kids have had infections, sores, superbug attack and so on. "ILLC is a Petri dish… the place is crawling with bugs. They use the cheapest mattresses on the market. It's like they want them [patients] to get sick" (74). Teddy Dobbs a patient burnt to death at ILLC due to the negligence of the staff that left him under hot shower unsupervised.

The title of the novel was inspired from an article Nussbaum read which centred on a disabled person who was suffocated to death for misbehaving, by the staff of the institution where he lived. Witnesses claim that the staff who suffocated him whispered, "I can be a good king or I can be a bad king" to his victim as he succumbed to death. Nussbaum says, that the title reminds her of all the power the staff have over the inmates. They have no emotional connection with the disabled due to which "terrible things happen in many institutions" (Interview).The staffs in many of these institutions refuse to empathise with the experience of the disabled and therefore are not motivated to treat them as human beings who could suffer from what was being done to them. Recent reports suggest that most often the staffs are underpaid and overworked.In the novel, a young boy Pierre had to be hospitalised as he was abused by his houseparent. The disabled people are denied autonomy when they are institutionalised against their will or when they are regarded as legally incompetent because of their disability."Powerlessness characterise the experience of residential care" (Morris 80).

> They have never owned a check book, purchased anything more expensive than a Mr. Frosty, they don't have first clue about banks or monthly statements or buying groceries. Mrs. Phoebe won't even let the kids take the bus alone because she says it's a liability issue. Everything is a liability issue. Eighteen and nineteen-year-olds are trained to stay helpless. So they have to stay institutionalised. (102)

"Society restricts their opportunities to participate in mainstream economic and social activities rendering them more or less dependent" (Barnes 5). "Accessibility should be seen as a public responsibility" (Wendell 64). According to The Department of Economic and Social Affairs, Accessibility can be defined as the "ability to access" the functionality and possible benefits, of some system or entity and is used to describe the products, devices, services or environments for people with disabilities. Everyone should be given access to opportunities to develop their potential. “Accessibility will help people who are hiding in the private sphere because of the assumptions that they live there to integrate with the public sphere” (Wendell 64). In the novel the character Joanne Madsen exposes the despicable condition of ILLC, “none of the staff bathrooms have accessible stalls” (70).

> … what with the inspections of one’s privates for explosive devices, the prospect of a broken power wheelchair in areas where local crips travel by wheelbarrow, and the ever-present dread of traveller’s diarrhoea with no wheelchair-accessible bathroom for miles, traveling is no vacation… Earth, is not a hospitable place for crips. (9)

Persons with disability are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services. In the novel, Mia Oviedo who suffers from cerebral Palsy is not allowed an electric wheel chair but a manual one to which she’s strapped into in order to prevent her from falling off. The inmates at ILLC claim that they are denied power chairs irrespective of the fact that most inmates like Mia are in dire need of one. This is because, “power chairs would give the kids more autonomy. Keeping them immobile makes it easier on the staff” (48).The novel in a way attacks the U.N. guidelines regarding accessibility and development (2013); “The state shall eliminate obstacles and barriers to accessibility. The state would make appropriate measures to ensure that persons with disability access on an equal basis with others” (Article 9).

The possibility of institutionalisation hangs over many disabled people fuelled by the ear that one day the support which makes their independence possible will disappear, or that an increase in functional limitations will prove too much for whatever resources are available to them. In the novel, ILLC forces Teddy to move to a different institution against his will, once he turns twenty two. It is the ILLC authorities that chart out his future and not Teddy himself; “they (ILLC authorities) say they’re sending me to Maywood (an institution for the disabled) way far away in two months. My dad’s gonna have to take fifty trains out there… I won’t never see nobody” (136).The disabled are merely objects in today’s world rather than the authors of their own lives.

To be admitted to one of these institutions is to enter a kind of limbo in which one has been written off as a member of the society but is not yet physically dead. Many of the institutions for the disabled thwart the accessibility of the disabled in most spheres of their life, so that they could be kept institutionalised. It is one of the many tactics adopted by institutions to keep the money rolling. Tim is the head of the ILLC administrative board.

While discussing with the board of ILLC about the numerous death at the institute due to negligence, he justifies the callous behaviour of his staff, “death is a natural part of life and unfortunately in our business we have to accept that there is going to be a lot more death than usual as people are frail” (192). Even though the rooms at ILLC are small, the profit minded Ted wants to squeeze in extra beds.

Dr. Caviolini who worked for ILLC used to order a lot of unnecessary tests from the patients with the aid of the ILLC staff. He looted “half a million dollar a year” from the Medicaid fund installed by the government for the welfare of the disabled (277).Thus, Nussbaum through her novel highlights the loopholes in the current legal system that is meant to protect the disabled. As long as an unequal power relationship exists between disabled people and non-disabled academics and professionals who make a living out of their needs, and as long as prejudice against disabled people is an integral part of our general culture, Disablism will continue to characterise the nature of the research done and the services provided. Nussbaum has skilfully incorporated the perspective of Michelle Volkmann a ‘patient recruiter’ at ILLC. Her job is to convince the families of the disabled to institutionalise their ward and thereby enable the facility to reap profit. She comprehends the viciousness of her job when she meets Cheri, one of the kids who gets institutionalised because of her; “She doesn’t move. The houseparent pulls her into a sitting position. It’s Cheri but not Cheri. Her eyes are almost closed and her mouth is open. When he lets go of her she slides back down in her bed” (219). Cheri suffered from schizophrenia but was content and healthy until she got institutionalised against her will and transformed to a “socially dead” (Morris 20). Hence the task of the society to the disabled who are institutionalised, is to cater for the socially dead, during the interval between social death and physical death.

The non-disabled society has done things for the disabled that has resulted in their segregation into special schools, residential care and their isolation within a physical, social and economic environment which does not address our needs. In the novel, the character Teddy Dobbs aspires to lead an independent life like any other adolescent his age but his disability restricts his freedom,“ Here’s Teddy’s vision of his future: He wants to live in an apartment, get a job, decide where he wants to go and when he goes to bed” (174). Disabled people assert the political demand for the right to live within the community in a non-disabling environment with the kind of personal assistance they can choose. In the novel Nussbaum makes her argument clear, “institutionalization is so medieval, so wrong and so very unnecessary” (Interview).

"The Disabled People's Movement understands disability as society's problem, and works to take down barriers which prevent them from taking our full and equal part in society" (Goodley 4).There are various allusions in the novel to protests carried out by organization that support disabled, like Access Now, established in 2009. The movement wants the disabled to be endowed with the right to be treated the same way as the non-disabled people in every area. However, these organisations have had to face repression from the state apparatus. Nussbaum portrays the protest carried out by one such organisation in the novel, "The police went crazy. They treated the crips violently there were even a few broken wheelchairs left in the street after they dragged the protestors to jail" (102). However, it is the perseverance of the protestors that paved way to laws that protect the welfare of the impaired. The Resolution of the United Nations in 1993; "Standard Rules for the Equalisation of Opportunities for Persons with Disabilities" and The Americans with Disability Act (ADA) upkeeps "equalisation of opportunities" for the disabled within the systems of society and the environment, such as services, activities, information and documentation.

Nussbaum in the course of the novel also introduces the Crip Theory which considers disability to be a viable identity variable to be recognised, acknowledged and celebrated (wright.edu). From a crip justice perspective, there exists a need to fight for equity and inclusion. Disability should be seen as a valued aspect of human diversity and not something to be pitied or feared. As the character Joanne Madsen says "I myself prefer "crip" or variations of "crip"… I find 'disabled' pejorative. Why not take back the king of all pejoratives, "cripple", and re-empower it by giving it the crip imprimatur" (106). Hence crip theory calls for action from within, rather than passivity. It points out that inequities and injustices inflicted on disabled people are violations of human rights that threaten the existence of the disabled people in the community.

Nussbaum in one of her interviews said, "I'm aware of my disability just about every day because every day someone will remind me of it… there will be sort of evidence of my otherness". It is to break such barriers that John Swain and Sally French developed the affirmation model of disability which seeks to "celebrate the difference" that characterise the lives of the disabled people. They rejected the notion of disability as a tragic concept purported by the medical model. By embracing the affirmative model the individuals assert a positive identity in being impaired and thereby repudiates the view of normality.

The contemporary society should establish infrastructure in which the needs and aspirations of disabled people can be met, with the appropriate range of services being provided. This can happen with adequate state funding, to assist organisations of disabled people to secure rights. Hence, it is ultimately disabled people themselves who are defining how they wish to live their lives. The organisations for the disabled must adhere to the principles of empowerment, and human rights, independence and integration, and self-help and self-determination. As Yessenia Lopez, one of the disabled patients in the hospital says, “Us youth come to these places on account of we got no place else to go and the least they could do is to take care of us and make sure nobody gets beat or raped or left in the shower by mistake and killed” (255). What appears to be a reasonable wish is a farfetched dream for a disabled. It is ultimately the society’s responsibility to enable persons with disabilities to live independently and participate fully in all aspects of life and “celebrate the difference”.

## Works Cited:

"Accessibility and Development: Environmental Accessibility and its implications for inclusive, sustainable and equitable development for all." *un.org*.June 2013. Web. 2 Mar. 2017.

"Crip Theory." *Wright.edu*. Web. 2 Mar. 2017.

"Susan Nussbaum's Social Engagemment." Interview by Emma Brown. *Interviewmagazine.com.* 23 May 2013. Web. 3 Mar. 2017.

Barnes, Colin. "Disability, Work and Welfare." *Disabilitystudies.ac.uk*. Sociology Compass.Web. 27 Feb. 2017.

French, Sally, John Swain. "Whose Tragedy: Towards a personal Non-Tragedy View of Disability." *Disabilitystudies.ac.uk*. Web. 27 Feb. 2017.

Goodley, Dan. *Disability Studies: An Interdisciplinary Introduction*. London: Sage Publications Ltd, 2011. Print.

Morris, Jenny. *Pride and Prejudice: Transforming Attitudes to Disability*. London: The Women's Press, 1991. Print.

Nussbaum, Susan. *Good Kings, Bad Kings*. London: Oneworld Publications, 2013. Print.

Shakespeare, Tom. "The social model of disability: an outdated ideology?" *.Disabilitystudies.ac.uk*. Web. 27 Feb. 2017.

Wendell, Susan. "The Social Construction of Disability." *The Rejected Body*. London: Routledge, 1996. Print.