



NOTHING ABOUT US WITHOUT US EMPOWERING PERSONS WITH DISABILITIES: A DEVELOPMENTAL APPROACH FOR THE MARGINALIZED

KEYWORDS

Persons with Disabilities, Marginalization, Empowerment, and Developmental Approach.

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ABSTRACT

The census 2011, which has covered only 8 types of disabilities, reveals that, India has 2.21% (26,810,557) persons with disabilities (PWDs). 'The National Centre for Promotion of Employment for Disabled People' argues that 5% to 6% of Indian population has a disability. An extensive study reveals that PWDs are one of the most disenfranchised and marginalized groups in India (Hiranandani & Sonpal, 2010). They are marginalized by denying their rights and as 'invisible' they are often side-lined in the rights debate and unable to enjoy equality, justice and dignity as everyone else. However, leaving on margins such a large group of PWDs no country can step into the frontier of developed nation. Hence, the need of empowering PWDs for their upliftment cannot be denied. The present paper gives (1) an overview of PWDs in India, (2) explains the concept of 'Marginalization' & 'Empowerment' and its indicators, and (3) analyses how disability and marginalization are interrelated and interdependent. This paper also explains (5) the need of understanding the interconnection of individuals and society for empowerment of PWDs and (6) various strategies for empowering PWDs.

Introduction

The World Health Organization (WHO) estimates that 10% of any population is disabled (Thomas, 2005). Recent estimates suggest 85-90% of the global population of persons with disabilities (PWDs) resides in so-called developing countries. In India, there are no clear estimates or projections on number of people with disability. Concerns persist that, given the stigma surrounding disability, many individuals with severe impairments, mainly women and rural disabled, are excluded from census and surveys (Jeffery & Singal, 2008). However, the census 2011, which has covered only 8 types of disabilities, revealed that, in India, 2.21% (26,810,557) of total population fall under certified PWDs category. It also reported that rural areas have more disabled people than urban areas. One of the leading NGOs in India namely The National Centre for Promotion of Employment for Disabled People (NCPEDP) argues that 5 to 6% of population has a disability in India. One of the annotations made by the World Bank (2007) was that 'the real prevalence of disability in India could easily be around 40 million people, and perhaps as high as 80-90 million if more inclusive definitions of both mental illness and mental retardation in particular were used.' However, in India, societies' misperception of different forms and types of disability and the limited capacity of social actors to accommodate PWDs often lead them towards exclusion or place them on the margins. Research reveals that PWDs are one of the most disenfranchised and marginalized groups in India (Hiranandani & Sonpal 2010). Thus PWDs experience marginalization, inequality and social injustice in their day-to-day lives, and have fewer opportunities to live as an effective and contributive member in an inclusive environment which can ensuring equality, equity and dignity in all spheres of life as other persons without disabilities enjoy.

Marginalization

Marginalization connotes a version being sidelined from participation in an activity, or in other words being able to participate, but yet at the margins. The statistics of PWDs as a sub-group, and the lived experiences of PWDs as individuals, more often reveal a picture of exclusion rather than marginalization. Exclusion consists of dynamic, multi-dimensional processes

driven by unequal power relationships interacting across four main dimensions - economic, political, social and cultural - and at different levels including individual, household, group, community, country and global levels. However, marginalization may also be viewed as a point on a continuum between inclusion and exclusion characterized by unequal access to resources, capabilities and rights which leads to inequality and injustice.

Disability and Marginalization- Interconnection and Interdependence

Disability is complex and multidimensional - how the individual experiences disability depends not just on the functional limitations relating to their impairment, but also on the environment. The UN Convention on the Rights of PWDs defines disability as resulting from 'the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others' (United Nations, 2006, Preamble Para. e). Attitudinal barriers range from assumptions about capabilities and dependency, which can lead to overprotection and disempowerment through to negative superstitious beliefs and practices towards PWDs. Negative attitudes towards disability mean that PWDs routinely experience discrimination within the family and community which can deny them equitable access to resources, services and opportunities for personal development. Environmental barriers include those in the built environment, such as inaccessible public buildings and those relating to communication including lack of information in accessible formats. As a result of discrimination and social exclusion PWDs themselves often suffer from low self-esteem, confidence and aspirations, all of which impact on their ability to participate equally in all areas of personal, social, economic, political, and cultural life. The type and severity of marginalization experienced by PWDs varies depending on the nature of their impairment, their environmental context, and the interaction with other factors such as gender, age, education, and socio-economic status. Whether an individual is born with an impairment, or acquires impairment through illness, accident or violence, the impact of disability accumulates across the life course: low levels of skills and high unemployment among

PWDs, for example, are often the result of a lack of access to education and other opportunities in childhood, which is compounded by the disability discrimination and barriers to employment. Similarly, inaccessible health services or public health information which fails to reach PWDs (for example because of their social isolation or because it is in inaccessible formats), can result in poor health outcomes which lead to further impairment and greater marginalization. PWDs in all societies can experience economic inequality as a result of their marginalization. DFID (2000) highlighted the relationship between disability and poverty. It was pointed out that disability could be the reason for poverty because it can lead to isolation and economic strain for the whole family, also the denial of education because of disability can lead to a lack of employment opportunities. Similarly, poverty can lead to malnutrition, dangerous working and living conditions (including road accidents) bad health and maternity care, poor sanitation, and vulnerability to natural disasters - all of which can result in disability. Study also showed that disability also affects households and the wider economy (Mitra et al, 2011).

Empowerment

The concept of empowerment was originated during the 'Civil Rights Movement' in the USA in 1960. The idea of power remains at the core of the concept of empowerment. However, in a simple way it can be stated that empowerment is a multi-dimensional social process that helps people gain control over their own lives and ensures human rights and social justice to disadvantaged or marginalized groups of people. It is a process that fosters power (that is, the capacity to implement) in people, for use in their own lives, their communities, and in their society, by acting on issues that they define as important. It is suggested that three components of definition are basic to any understanding of empowerment. Empowerment is multi-dimensional in that it occurs within sociological, psychological, economic, and other dimensions. Empowerment also occurs at various levels, such as individual, group, and community. Empowerment, by definition, is a social process, since it occurs in relationship to others. Empowerment is a process that is similar to a path or journey that one develops as he/she works through it. Other aspects of empowerment may vary according to the specific context and type of people involved, but these remain constant.

Understanding Interconnection of Individuals and Society for Empowerment of PWDs

In addition, one important implication of this definition of empowerment is that the individual and society are fundamentally connected. Wilson (1996) pointed out that recently, more researchers, organizers, politicians and employers recognize that individual change is a prerequisite for community and social change and empowerment (Speer & Hughey, 1995; Chavis & Wandersman, 1990). This does not mean that we can point the finger at those with less access to power, telling them that they must change to become more like "us" in order to be powerful/ successful. Rather, individual change becomes a bridge to community connectedness and social change (Wilson, 1996). To create change we must change individually to enable us to become partners in solving the complex issues facing us. In collaborations based on understanding, mutual respect, diverse perspectives, and a developing vision, people work toward creative and realistic solutions. This synthesis of individual and collective change (Wilson, 1996; Speer & Hughey, 1995) is our understanding of an empowerment process. Therefore, it can be stated that the upliftment of the marginalized PWDs from margins and creating a sustainable change in society or entire system is only possible when persons with disability will be empowered individually in a collaborative way.

Major Indicators of Empowerment

According to Naila Kabeer, Linda Mayoux, Anne Marie Goetz, Rahman, Ackerley, JSI (John Show International researchers), Sara Longwe and Hashmi the major indicators of empowerment are provided below:

JSI Six Domains of Empowerment

Domain	Expressions
1. Sense of Self & vision of a future	Assertiveness, plans for the future, future-oriented actions, relative freedom from threat of physical violence, awareness of own problems and options, actions indicating sense of security.
2. Mobility & visibility	Activities outside of the home, relative freedom from harassment in public spaces, interaction with others persons without disabilities.
3. Economic security	Property ownership, new skills and knowledge and increased income, engaged in new/non-traditional types of works.
4. Status & decision-making power within the household	Self-confidence, controlling spending money, enhanced status in the family, has/controls/spends money, participation in/makes decisions on allocation of resources, not dominated by others.
5. Ability to interact effectively in the public sphere	Awareness of legal status and services available, ability to get access to social services, political awareness, participation in credit program, provider of service in community.
6. Participation on non-family groups	Identified as a person outside of the family, forum for creating sense of solidarity with other women, self-expression and articulation of problems, participating in a group with autonomous structure.

(Source: John Show International researchers)

Strategies for the Empowerment of PWDs

The following strategies can be taken for the upliftment of the PWDs

1. PWDs remain largely marginalized, frequently unemployed, and voiceless and excluded from civil and political process due to their lack of awareness about their rights and entitlements. Therefore, they must be made aware of their rights and entitlements.
2. Quality and need based education must be imparted among PWDs at free of cost in an inclusive and enabling environment.
3. Evaluation and reformation of the existing developmental strategies, policies, legislations and schemes must be done and new sound strategies, policies, legislations and schemes have to be framed and implemented in an appropriate way to ensure equity and equality for PWDs.
4. Agricultural practices (rearing of grass cutters, poultry, fish, snail, quail, cassava farming and its processing etc.) can help PWDs to become economically vibrant, employees, and support their family also.
5. Enlightenment, awareness, and sensitization campaign is very necessary regarding various opportunities and govt. provisions available for survival and development of PWDs.
6. Medias like; TV, radio, theaters, etc. and social networks like; face book, twitter, what'saap, etc., can play a vital role in spreading awareness and inculcating positive attitude among all citizens about PWDs.

7. The government, corporate organizations, politicians, and philanthropists must have strong will to empower the PWDs by providing them adequate facilities and protecting their rights.
8. Having access to information is another gateway to the empower PWDs. Therefore, it is important that there should be an ICT center for PWDs in each school where constant training on ICT should be provided to update the knowledge of the PWDs in aspects of life.
9. The reservation policy that has been mandated by govt. of India should be strictly followed by both govt. and private sectors ensure employment security for PWDs.
10. Finally, accessibility of the physical environment must be ensured in order to help PWDs in achieving greater independence, participation and social inclusion.

Conclusion

The numbers of PWDs in India is quite large and this group is significantly marginalized and deprived of enjoying their basic human rights. Very little attention has been devoted to their upliftment from both government and individual perspectives. No country can step into the frontier of a developed nation leaving such a large group of PWDs on margins. In Addition, when PWDs are empowered adequately to participate and lead the process of development, their entire families, communities and even the larger society will benefit because their involvement creates opportunity for everyone with or without disability in any developmental effort. Therefore, empowerment of PWDs must be given due attention and ensured for national development as a whole.

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