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RESEARCH ARTICLE

Reducing Inequality for Persons with Disabilities

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Abstract: Disability and development are about power, access, solidarity, advocacy, inequality, rights, voice, and support. It is about accessing accessibility. It is important to understand the politics of language—how we conceptualize persons with disabilities. Disability is heterogeneous in nature. Each person has disabling parts and "normal" parts. As human beings, representations are critical to understanding and experiencing the world. Representation helps one to know what is awful, reprehensive, acceptable, possible, desirable, etc. Sometimes our lives are represented in ways that do not match how we experience the world. Other times, representations articulate our lives and experiences in ways we may be unable to express. Representations structure reality. Hence, they can be a critical component in bringing about rights. It is crucial to look at the needs and challenges at the ground level in a different context. Understanding why survival is considered sufficient and not full participation is important. Policies need to resonate culturally. Otherwise, they tend to be confined to particular classes and groups in societies with access to technology, information, and the English language. What matters is the visibility of disability.

Keywords: disability, representation, policy, sustainable development, rights

1 Introduction

It is important to understand the politics of language—how we conceptualize persons with disabilities. It is about the way and word(s) a person uses to address persons with disabilities. R. D. Laing, a Scottish psychiatrist, said we use complex terminologies to put a stop to experiences that are difficult to explain (Laing, 1967). The best practice here would be incorporating terms with genesis in the immediate experience of persons with disabilities. It is crucial to treat them as "experts by experience" (Rose, 2019). Disability is heterogeneous in nature. Each person has disabling parts and "normal" parts. As human beings, representations are critical to understanding and experiencing the world. Representation helps one to know what is awful, reprehensive, acceptable, possible, desirable, etc. Sometimes our lives are represented in ways that do not match how we experience the world. Other times, representations articulate our lives and experiences in ways we may be unable to express. Representations structure reality. Hence, they can be a critical component in bringing about rights. Policies need to resonate culturally. Otherwise, they tend to be confined to particular lases and groups in societies with access to technology, information, and the English language. What matters is the visibility of disability.

Disability and development are about power, access, solidarity, advocacy, inequality, rights, voice, and support. It is about accessing accessibility. Disability is defined, interpreted, and experienced differently—through social, cultural, political, and legal discourses in India (Ghosh, 2016). There was a paradigmatic shift around the 1960s-70s in how disability was understood—from a personal medical problem to the social and political one. Medicine, as useful as it is, also, unfortunately, concretizes its definition of disability as it focuses on functionality and its limitations. In the physical or sensory deficits, the lived experience gets foreclosed. As disability is a multidisciplinary perspective, the response to disability is varied as well. Disability is a development issue, and it influences all aspects of development. It is not an NGO element. The report also highlights the essential element of intersectionality. Disability is related to gender, caste, class, and poverty and is not in isolation. Can this report be equated to development taking a deaf turn?

2 Critical Perspective

Disability represents various conditions and impairments: congenital, acquired, visual, locomotor, sensory, genetic, intellectual, and mental (psychosocial). Disability either receives public gaze or is rendered invisible. Nandini Ghosh writes, "The most common experience is while people stare at and comment loudly about the disabled person, no one ever speaks to them directly" (Ghosh, 2013). Disability is ubiquitous, yet it evokes existential terror, anxiety, and fear. There is a need to pay attention to culture as culture plays a vital role in giving context and meaning to the experience of disability. There is a need for qualitative research into mental health in non-western settings. We should also be aware of the movement from the center to the periphery. When psychotropic pills transition from the Ministry of Health to the clinic, the focus shifts towards enhancing accessibility and participation, ultimately emphasizing their role in the treatment process (Jain & Jadhav, 2009). Certain institutes are dominant and play a central role. There is a need to incorporate multiple voices in primary mental health care and the model of disability through the primary health care system. It is crucial to focus on the needs brought forth by persons with disability. Sustainable development cannot take place if the psychosocial aspect remains foreclosed.

Is the element of social/relational getting shifted to a more individualized being? I would say an individual is relational, and where there is relationality, there is sociality. The paradox of disablement as enablement is important and poses challenges for people working with individuals affected with leprosy and for disability activists and policymakers (Staples, 2005). Policy making and advocacy require the erasure of different kinds of disability, resulting in homogenization, and "development actors work hardest of all to maintain coherent representations" (Mosse, 2004). Policy and decision-makers are not often aware of assistive technology and the help they bring. Practice must give rise to policy (Mosse, 2005). Lived experiences may differ as disability is also seen by some people as enabling (Staples, 2005). At the level of policy-making and documentation, one should be aware of how *disablist* and '*abliist*' ideologies subtly inform the process. Disability needs to be looked at as diversity and not as deviant. The idea is to embrace diversity and then fit it into normative. The perspectives of caregivers and family members also need to be incorporated. Disability is an important axis in development interventions (Grech, 2015).

Global mental health discourse has shifted since 2007 as mental health is also articulated as a development issue (Mills, 2018). Here too, disability is seen as a development issue. The discrimination emanates from the point that disabled bodies are unproductive. That they do not contribute to development. There are strong links between disability and poverty. Rights-based approaches in disability studies and development interventions are aligned with each other. We need perspectives from Global South as the field of disability and development has been dominated by the Global North.

The question: development *for* whom and *by* whom becomes important. The question of development can be understood by research on disability. Question of disability by what real-life experience from the field show, and it needs to bring global south concerns. A third important aspect is the question of methodologies. We need to look at practice and processes. Hence, the methods of studying should not be static—they must be able to access the processual nature of lived realities of everyday lives. There is a need for qualitative and participatory empirical research, capturing complexities and paradoxes, resulting in interdisciplinary, theoretical, and critical insights. Development as an effort of the civilizing—modernizing mission having colonial origins. The irony of the 'development industry' is that colonial encounters resulted in economic exploitation, death, and disability.

Reducing inequality for persons with disabilities involves social, economic, and political inclusion. The focus is not on erasure but on inclusivity in spaces and institutions. The report is premised on action; that is, the report covers work that countries are doing to make the world better and fairer for everyone. All seventeen Sustainable Development Goals (SDGs) are interrelated and have an intersection with gender, poverty, etc. Reducing inequality for persons with disabilities is related to their education, safety, reduction of poverty, and so on. Inequality can be looked at from various layers. Access to healthcare becomes compromised, affording a wheelchair becomes challenging, and paying electricity bills gets difficult. Often, people with disabilities are left out of plans and decisions about their local areas and countries.

3 What Needs to be Done? Government Policies and Implementation

The primary objective is to observe how laws, rules, plans, and services function for individuals with disabilities. Understanding how to create effective laws and services for people with disabilities is crucial. Additionally, the challenge lies in providing support and inclusion for individuals with disabilities during natural disasters or war. They should be able to get adequate financial aid however, there should also be structures and frameworks which help persons with disabilities earn their livelihoods and have full say in making their own life choices. Their independence will also become a marker of their development. One step towards inclusivity is providing good education for persons with disabilities in the same classroom as persons without disabilities. Persons with disabilities should have information about their rights and be involved in planning and decision-making. There is stigma and discrimination related to the disability; there is a lack of accessibility to physical and virtual environments, access to assistive technology, and support for independent living, and all these aspects are crucial for full and equal participation as agents and change.

Access to assistive technology will help to ensure the independent living of persons with disabilities and their full participation. However, in developing countries, more than half of persons with disability are not able to get assistive products. Either the products are inadequate, unaffordable, or there is no transport for their distribution. Although the document stresses deinstitutionalization, Nakamura's (2013) study on Bethel House shows that community living and supportive relations are provided, which sometimes psychiatric institutions do not provide adequately. Institutions have different shades and colors, and what institutions mean in different contexts varies.

4 Government policies for disability intervention

Attempts must be made to de-medicalize and de-specialize the field of disability and to bring it into everyday conversation. Disability is an issue that concerns all of us for its ramifications for notions of the 'normal.' It must be seen as a public health, rights, and development issue. Regarding policy formulation, cross-disciplinary access is required in psychology, sociology, disability studies, sociology, anthropology, etc. There is a need to bring academic sharpness and first-person narratives, which can help the policies to be informed by the everyday challenges. Under the Ministry of Health and Family Welfare (MoHFW), Government of India, there are departments such as Blindness Control, Mental Health Division, Medical Education, Bureau of Planning, Emergency Medical Relief, Central Design Bureau, National Programme for Health Care of Elderly (NPHCE), National Programme for Control of Blindness (NPCB), National Programme for Prevention and Control of Deafness (NPPCD), NGO Division, etc. that are directly or relationally associated with disability planning and programs.

When the talk about the Indian context, with its “federal structure,” “the responsibility of the government-led health effort lies with each of the constituent states of the Indian republic, and not with the central government, as, for administration, health services are a state subject" (Sarin & Jain, 2017, p. 714). This is evident in the actions of policies catering to different forms of disabilities. The decentralization appears theoretically sound. However, in practice, the programs such as NPPCD and NPHCE are funded and steered by the Central Ministry, the Ministry of Health and Family Welfare (MoHFW), and their execution takes place at the state level. It has been noted that the communication between and within various ministries may lack the required rigor (Sarin & Jain, 2017). Furthermore, the difficulty is confounded by the fact that various actions like formulating the annual reports for intellectual disability and policy suggestions are given by the Department of Empowerment of Persons with Disabilities (Divyangjan), which falls under the Ministry of Social Justice & Empowerment, Government of India instead of the Ministry of Health. It has been stated that the "communication and collaboration between the two Ministries has not always been characterised by either harmony or accord" (Sarin & Jain, 2017). The challenges thus are the absence of standardization of care and maintaining quality standards. There is a need to break the silo between specialized care for the non-poor in the private sector and an administrative community mental health for those having a BPL card.

Thus, the Rights of Persons with Disabilities Act, 2016, which replaced the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, also states that the focus must be on individual autonomy. The solution is not the policy that chooses what is right for persons with disabilities. However, the environment and schemes must be designed in such a way that people have an agentic force with them to navigate through their needs and the facilities provided.

The Village Health Sanitation and Nutrition Committee (VHSNC) has been asked to the "vulnerable sections" such as "the marginalised, the socially excluded, the poor, the old and the disabled" (National Health Policy, 2017). Yes, there is a dire need for trained professionals who can cater to the needs of persons with disabilities from a poor section of society which would mirror realistically the complex reality of disability care. Additionally, the marginalized are represented as needing more doctors and more technology in academic reports, government policy documents, and NGO documents (Ecks & Sax, 2005). The voice, experiences, and coping styles of the marginalized need to be included in the imagination of the ordinary person and policy formulators. Ill health arises as much from the health system's failure and poor planning as it emerges as a product of the development process itself. There is a need to promote research on social determinants of health, as the policy mentions that disability is a "neglected health issue" (National Health Policy, 2017, p. 26). There is a need for specialized professionals in disability care and research in 9 National Institutes and 21 Composite Regional Centres (CRCs) established by the Department of Empowerment of Persons with Disabilities (Divyangjan) under the Ministry of Social Justice and Empowerment. There are 6 CRCs whose website is not formulated and various CRCs with a faculty shortage. By increasing the workforce, conducting research on social determinants of health, bridging the gap between specialized private sectors catering to the affluent and tertiary services for others, and empowering Disability Studies as a discipline in India, we can bring about significant transformations in theoretical advancements and disability advocacy within the country's local and national contexts.

5 Discussion

When compared to UK or USA, the trajectories of India are different as there is a large population and multiplicity of marginalization. Disabled people are not only constructed as 'Other' but 'the Other' of 'the Other' (Ghai, 2015). Anita Ghai has played a major role in developing Disability Studies as a discipline in India that can transform theoretical advances and metamorphose disability advocacy (Ghai, 2015). It is crucial to look at the needs and challenges at the ground level in a different context. It is important to understand why survival is considered sufficient, and policies do not emphasize full participation. Even when discussing rehabilitation, we are pointing towards *just* meeting the criteria to live a “normal” life. Although what we mean by “normal” is an endless debate. The importance of technology cannot be neglected. However, technology is not only about an inanimate “object” or a “thing.” It is also marked by requirements and access. Inclusion is also about access to development. At the level of policy-making, documentation, and research, it is important to see what terms are used in the local context. They might be translatable, but something is lost in translation as words have meaning(s), context(s), and histories. It is important to examine how the community frames itself and what is being enabled through new capabilities made available through spaces and institutions. Rehabilitation is not a total solution to providing an empowering future for persons with disabilities. The question arises: rehabilitating towards *what,* and *who* has imagined and conceptualized what is considered rehabilitation? When we address Sustainable Development Goals (SDGs), all seventeen intersect with gender and poverty. Hence, until the disability is not understood and experienced as a developmental issue, one cannot think beyond rehabilitation. In that sense, we must understand the intersections between pathways that can yield financial, social, and moral freedom to persons with disabilities. Hence, multifold relationalities between disability and development, which is understood as a path to have one's agency in life choices, need to be revisited as Disability and development are related at social, moral, political, and economic levels. Indeed, “care of the ill individual continues to be the primary responsibility of the family and the local community (rather than the State)” (Sarin & Jain, 2017).

Disability is not only a personal medical problem but a sociopolitical one. Disability is not about 'us' and 'them' as it is a continuum that most humans experience. The policies must be framed in a way that demonstrates the speech of a speechless person, including the experience of the people for whom the policies are framed. Disabilities are frequent, “which affect the functionality in old age, compromising the ability to pursue the activities of daily living” (NPHCE, 2010). User-led research is essential because it strongly advocates for including individuals with disabilities and amplifies their voices. The data gathered through this approach is valid and potent and goes beyond just addressing rights and discrimination issues. One must incorporate first-person narratives as persons with psychosocial disabilities are “experts by experience” (Rose, 2019). When we look at micronarratives from the field, authentic documentation would be possible, which would not foreclose the contextual and varied elements from the field.

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