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978-1-107-06406-5 - Disability, Education and Employment in Developing Countries:

From Charity to Investment

Kamal Lamichhane

Excerpt

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1 Fundamentals of Disability Studies

Introduction

Human beings are bestowed with strengths, and the communities we make up are the sum of all our individual strengths. However, when one individual lacks strength in an aspect that another takes for granted, we tend to forget that each of us is blessed with different and sometimes complementary strengths. Where one is lacking or inadequate in ability, another might naturally find a task easier to accomplish. In this way, the involved parties recognize and efficiently utilize each others' strengths for a mutually beneficial situation.

This concept can be related to the economic theory of comparative advantage (Ricardo 1817), which argues that net benefits can be gained among trading countries when one specializes in a good in which it has a comparative advantage (the ability to produce a good using fewer resources than another country), and then trades that good for a good in which another country enjoys comparative advantage. This draws on the individual strengths of each country and leads to a win-win situation. It is necessary to encourage societies to recognize each other's differences as complementary and to see strength in diversity. However, the inability to recognize these complementary strengths – poverty of awareness – is the reason why disability issues do not get adequate attention in government policies around the world.

When we begin to focus on what someone lacks instead of what someone has, our thoughts are steered in a negative direction that causes us to forget that human beings are, by nature, mutually interdependent. Diversity is natural among human beings. Hence, the assumption that all human beings are similar and have the same facility for carrying out various activities is a rejection of the notion of human diversity and individual difference. It could be argued that the difference in our ability to perform an activity stems from an individual lack (whether physical, mental, or emotional), but such an argument ignores the reality that an individual functions within a society or state institutions, and that this 'lack' might be imposed from the outside. Differences in our ability to perform activities arise mainly as a result of external environmental

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factors (i.e., to say, a disabling environment) that deter a society, community or individual from reaching their full potential.

If external barriers (such as the lack of accommodation or support) are not removed or dealt with, people, regardless of any functional limitations or other individual differences, will face difficulties in carrying out day-to-day activities. The question to ask is, does the responsibility for removing such barriers lie within the individual or the society? Let us consider a hypothetical example. Consider society before the invention of escalators, elevators and the like. If buildings were built without stairs, people would not be able to reach the upper floors on their own two feet; and since everyone then would share the same difficulty, no one would be looked at differently for being unable to access the upper floors. Stairs in buildings became the norm to enable (the majority of) people to gain access to upper floors, since most people have two legs and are able to utilize stairs. There is no doubt here: The responsibility for building stairs to remove the barrier to accessing the upper floors lies with the entity within which individuals exist. Now everyone is able to access upper floors, except those who are unable to walk upstairs unassisted.

When one type of people are in the majority, in this case, let us say 'normal' people, facilities are designed for their convenience, and people who are regarded as not being 'normal' may suffer negative consequences. Hence, facilities designed for the majority of people are regarded as natural, and minority groups who face difficulties because society fails to accommodate their needs are regarded as not being 'ordinary' or 'normal'. As a result of their functional limitations or physical differences, people with disabilities who are not regarded as 'ordinary' represent nearly 15 per cent of the global population (WHO 2011).

If there were no ramps or elevators, wheelchair users would face barriers in accessing the upper floors of buildings. Since only a small population face these difficulties in a society where ease of access is taken for granted by the non-wheelchair users majority, such externally imposed barriers tend to be overlooked. If the responsibility for building stairs lies with the entity within which individuals exist, should the entity not also be responsible for ensuring that it is also the norm for wheelchair users to be able to gain access to upper floors? Discounting the influence of a disabling environment and instead pointing the finger at the inability of individuals themselves creates problems and cultivates deficit-based thinking.

Our concept of externally imposed barriers evolves with time and the evolution of human society. Another example of how disabling environments are created as byproducts of technological evolution is the telephone.

The development of this technology meant that businesses began to respond to clients' needs on the telephone, effectively disabling people who have hearing difficulties. However, with the advent of e-mail, people with hearing difficulties were freed to communicate with others, thus removing barriers in their work environment. Herein lies the fundamental question: What makes a disability, and when does a physical condition become a disability?

Theoretical concepts of disability

In disability studies, there are two main threads to the concept of disability: the medical model and the social model. Both models regard disability as a difficult predicament commonly faced by people; however, while the medical model looks at disability as a condition requiring medical intervention, the social model looks at it as a condition that requires the transformation of societal attitudes and state policies (Silvers 2010).

The medical model

The twentieth century saw the invention of new technologies such as radio and television, which helped ease the lives of people with visual and hearing impairments, respectively, who had few or no alternatives previously. Revolutionary developments were also made in the fields of science and medicine. These contributed to a society that was growing more aware of disability and illness from a medical viewpoint, with increasing possibilities for cures or interventions. The massive numbers of casualties that resulted from the Second World War had to be provided for in the form of pensions or medical assistance. This led to a pressing need to define eligibility criteria for people with disabilities so as to facilitate the process of obtaining assistance, which served as the basis for the development of the medical model of disability.

The medical profession views impairments as the result of various health-related factors which can be identified, confronted and/or eradicated through medical treatment. The medical model focuses on the limitations of individuals and looks at medical interventions or adaptive technologies to allow them to (re)-adapt to society. An example would be cochlear implants that help provide a sense of sound to people who are hard of hearing. Treatments are welcomed most of the time. However, medical treatment by professionals within institutional settings began to disregard the other needs of people with impairments, including their psychological needs. People with impairments had

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little freedom of choice and they were not actively involved in deciding about their treatment and its process. Rather, they were mostly regarded as passive recipients of charitable services decided by others. Through its specialized knowledge and the assumption that impairment is a problem or disease to be cured, the medical perspective on disability denies people with impairments their freedom of choice – the choice to decide what kind of life they want to live. More precisely, this traditionally dominant medical model perceives individuals' functional limitations as problems and looks for a diagnosis so as to find a solution, with the primary focus on considering what is wrong so as to improve the person with disability such that they can adapt to a world that itself does not accommodate their limitation.

Admittedly, alongside evolving definitions of disability, the medical model itself has evolved with technological and medical advances. Today, with myopia becoming an increasingly common (and thus 'normal') condition in post-technological modern society where reading and other close work is carried out on a daily basis, wearing glasses is no longer considered uncommon and not even viewed as a form of medical intervention. Although pre-technological society did not have to deal with this problem on a large scale, modern society has come up with efficient and affordable strategies so that the general population can deal with poor vision. A person in the hunter–gatherer period with poor eyesight would not have been able to carry out many socially expected tasks; but today, glasses, contact lenses or even corrective surgery have become increasingly normal such that poor vision is no longer considered a problem that deters someone from taking part in society. However, the unchanging characteristic of the medical model is that it seeks to intervene in the condition of the person to overcome their functional difficulties so that they can adapt to their roles in society. This outlook gave rise to the second model of disability – the social model (Oliver 1983; Oliver 1990).

The social model

In critiquing the medical model, the growing perception from the 1960s was that people with impairments were also entitled to freedom of choice and should not have to rely merely on assistance and charity dispensed by others. Societies began to demand more democratic forms of government in which individuals had freedom of choice and were not deterred from participating actively in society. New and emerging societal values began to shape societies that advocated improving the lives of marginalized groups, for example, people with impairments, women, children and elderly people. This led to

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the introduction of the social model of disability, which identifies systemic barriers, negative attitudes and exclusion by society (intentional or inadvertent) and argues that societal attitudes and environment are the main barriers for people with disabilities. There are two dimensions to the social model – changing social attitudes and, correspondingly, influencing state policies. Although state policies can be amended or implemented in a relatively short period, the changing of social attitudes might take place only over generations, and so relatively short-term state policies do tend to be a reflection of embedded social attitudes.

In contrast to the medical model, the social model looks at disabilities as social rather than natural deficits (Silvers 2010). It provides a way of conceptualizing the difficulties experienced by people with impairments as social deficits, through the barriers that are set against their participation in socio-economic spheres (Burchardt 2004). In doing so, it attempts to restore the rights and interests of people with disabilities, calling for social reform instead of medical intervention to address the difficulties they encounter. The strength of the social model lies in how it empowers people with disabilities to greater freedom in social participation through calls for social reform instead of the passive receipt of medical intervention.

There have been debates within the disability movement regarding the precise interpretation of the social model (Oliver 1996). One commonly accepted characteristic of the social model is the distinction it makes between an impairment and a disability. As discussed earlier, impairment is a condition of the body or mind, such as lacking legs or hands, vision or hearing loss or depression. It is an attribute of the individual. Disability is the loss or limitation of opportunities to participate in activities – social, economic and political – on an equal footing with those with no impairments, which is the result of the social, economic and physical environment being inaccessible to these people. Late Finkelstein, an advocate on the concept of disability, thus argued that ‘Disability is the outcome of an oppressive relationship between people with impairments and the rest of society’ (1980, 47). Similarly, Oliver and Barnes (Barnes et al. 1999; Oliver and Barnes 1998) emphasize society as the cause of disability and reject the idea of it being a personal tragedy. If barriers to full participation are not intrinsic to the individual but are rather social in nature, it is a matter of social justice that these barriers should be dismantled (Barnes et al. 1999; Oliver and Barnes 1998). In addition, Shakespeare (2011) commented that people with impairments have problems partly generated by those impairments and partly generated by the way societies fail to respond adequately to those impairments.

The evolution of models of disability

In this context, the social and medical models seemed to form a kind of dichotomy, each offering a perspective that the other was lacking. However, more recently other disability models have developed by extension from these two seemingly divided models, offering a reconciliation of their ideas. The Nagi model, stemming from the 1960s (Nagi 1965), looks at the concept of disability as a social construct and views disability as a functional limitation. In a national agenda report (Nagi 1991), functional limitations were identified as (either objective or perceived) restrictions in daily life and in achieving what is socially expected, as a result of physical impairments imposing on the individual's ability to perform his or her roles and normal daily activities.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) was established by the World Health Organization in the 1980s as the first internationally known system to classify the consequences of diseases. Two decades later, it was revised and renamed the International Classification of Functioning, Disability and Health (ICF; WHO 2001), with a new emphasis on the environmental factors that create disability. In the ICF, functional problems are categorized in three interconnected areas: impairments refer to the problems of body function or alterations in body structure – for example, paralysis or blindness; activity limitations refer to difficulties in executing activities – for example, walking or eating and participation restrictions refer to problems with involvement in any area of life – for example, facing discrimination in employment or transportation.

Taking the perspective of one or more of the above models, there are a significant number of research studies and books in disability studies regarding the definition and concept of disability, and a few include the perspectives or experiences of scholars and activists. However, the theoretical concept of disability studies and its definition is still evolving. Disability is essentially a highly contextual aspect of human diversity in which common understanding is difficult to achieve, unlike disciplines such as education, economics and pure science. It should also be understood that disability scholars acknowledge that no single theoretical framework to date defines disability.

Disability and Sen's capabilities approach

In the 1980s, Amartya Sen introduced the concept of the capability approach, whose core component is its distinction between functioning and capabilities.

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Although one's 'functioning' refers to 'the achievement of a person', the 'various living conditions' of 'what he or she manages to do or be', 'capabilities' refer to a derived notion of the 'ability to achieve them' and 'a person's freedom to choose between different ways of living' (Sen 1987, 2003).

The capability approach focuses on human achievement and freedom, as well as the need for reflective evaluation, which provides a useful framework for looking at highly contextual disability issues. In particular, some researchers discuss the synergy between the capabilities framework and the social model of disability (Baylies 2002; Burchardt 2004; Mitra 2006). While the social model of disability evolved through the struggle for the realization of civil rights, the capabilities framework was developed in rejection of the utilitarian notion of value in individual utility and proposes to replace it with capabilities, whereby the freedom and availability of opportunities for people to achieve what they want to do or be is considered.

The capabilities framework provides a general theoretical framework in which to locate the social model of disability since it looks at how the functioning of an individual interacts with the external environment to define the individual's capabilities. Burchardt also highlights common themes between these two approaches, such as the relationship between social barriers and individual limitations, the importance of autonomy and the value of freedom and dissatisfaction with income as a measure of well-being. More specifically, the capabilities framework measures well-being in terms of the 'capability set of the individual', whereby '[i]nequality is ... assessed by the distribution of capability sets among people' (Burchardt 2004). The concept also provides sufficient and flexible space to introduce the discussion of undefined and undetermined issues, as well as having the capacity to come up with tools to resolve them. This approach later gained prominence when it became the basis for the development of the Human Development Index and it remains the foundation for perspectives on development issues in the United Nations (UN, 1994).

Shifting the paradigm from charity to investment

The investment approach to disability

In seeking to improve the well-being of people with disabilities and to recognize their strengths and potentials, it is now time to address disability with an investment approach rather than through charity. The problems faced by

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people with disabilities demand a paradigm shift from charity to investment. As discussed in the previous section, people with disabilities are not lacking in abilities; rather, they have varying and different potentials, which can be maximized, harnessed or developed through proper education and training. The traditional charitable approach in essence assumes people with disabilities to be passive recipients of pity who require sympathetic help. The relegation of responsibility for disability issues to charitable organizations ensured their continued exclusion from mainstream society.

The word ‘charity’, derived from the Latin word *caritas*, has been widely used to mean the duty of helping others who are generally regarded as weaker, or more needy, or having lower status than those who offer help. This notion is reflected in most of the world’s religions including Hinduism, Buddhism, Christianity and Islam. In Latin, *caritas* connoted preciousness or high price. As human beings, everybody requires charity and sympathy depending on their circumstances; however, the word ‘charity’ and the phrase ‘charitable approach’ have been largely used in the context of disability with the notion that people are subject to others’ mercy and are thus the recipients of something from others. Although those who help are not wrong to offer their help, the important issue is how to promote the rights and dignity of people with disabilities. When someone helps people with disabilities by donating food, clothing, shelter or whatever, these helping hands show an unfamiliarity with or even deny the idea that making the environment disability-friendly and investing in human resources can make significant changes to these people’s lives and impact the entire society.

This is because the notion of charity generally does not recognize the recipient as equal to those who offer support; from the perspective of givers, receivers (in this case, people with disabilities) manage to live their lives only through the support provided. As long as this concept persists, the identity and dignity of people with disabilities is hard to realize. Charity does not in general benefit the whole; rather it helps particular individuals or groups for a certain period of time, and there is almost no right to express dissatisfaction about the voluntary help offered. Moreover, from the religious point of view, the recipients of charity are regarded as unfortunate to be impaired, and prayers are offered for them, indirectly encouraging them to accept that their impairments may be the will of God.

Thus, sympathetic support is not permanent and sustainable. Whether indirect or direct, the charitable approach regards people with disabilities as individuals who cannot enjoy their lives without others’ support, who cannot support themselves and it regards their impairments as an unfortunate fate.

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This is one of the main reasons why the charitable approach needs to be changed to an investment approach, so that people with disabilities can be regarded as equal citizens and recognized in national policies geared towards realizing their participation in society and economic empowerment. Having said this, I am not in favour of rejecting completely the aspect of charity; however, in the case of people with disabilities who have experienced inequality, discrimination and poverty through prejudice and disabling barriers, the continuation of the charitable approach will not help them to realize their identity, promote self-esteem and achieve social inclusion and economic independence, nor encourage us to enjoy the beauty of living in the world with greater acceptance of human diversity. This is because the charitable approach does not increase the acceptance of people with disabilities in society.

The exclusion of disability issues from mainstream development might therefore be partly attributable to the charitable perspective on disability, in which the influence of the medical model may be much stronger. However, instead of emotional expressions based on sympathy, what people with disabilities need most is the opportunity to develop their potential and thus open the door to other opportunities. To realize a just society for all, investment in people who are vulnerable to the risk of falling into poverty is indispensable. The ultimate goal should be to create a comfortable society for all in which people both with and without impairments can stand shoulder to shoulder and work together. However, disability is not yet regarded as an area of investment; rather, it is viewed mainly from the charity-based perspective. To some extent, our poverty of awareness is the main reason why disability issues do not receive adequate attention in national policies and programmes.

Although few studies have touched specifically on the value of investment in people with disabilities, some have discussed this with regard to the general population, taking on the perspectives of inclusion and equality. Most acknowledge that equality is the central concept of inclusiveness, even if views differ on what type of equality is to be achieved. In this book, the term 'investment' is defined as the allocation of budgets and resources by states and societies into areas of human capital formation such as education, health and employment, and for social capital such as accessible roads and transport and other infrastructures, so as to facilitate the participation of people with disabilities in economic, social and political spheres. Although the concept of investment exists traditionally in the fields of finance and economics whereby there are expectations of dividends and production output, this book calls for socially responsible investment that seeks to promote the rights of people with disability. The focus of this book is the education–employment nexus for people

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with disabilities, and achievement in these two areas requires both investment in the formation of human capital as well as social inclusion in development. Appropriate investment in social capital helps to reduce barriers for people with disabilities and can positively result in their accumulation of human capital.

The field of disability studies has only recently progressed to the point where it is addressing issues of development. Moreover, there is a significant gap between developed and developing countries. Researchers in developed countries have already started to investigate the conditions that are necessary to improve the quality of life of persons with disabilities. Yet in developing countries, such studies remain rare, with less than 20 per cent of disability studies-related research found in developing countries, despite the fact that about 80 per cent of the world's population of people with disabilities is to be found in the developing world.

As discussed earlier, in recent decades, the conceptualization of disability at both the national and the international level has attracted increasing attention, especially in developed nations. I argue that concepts of inclusiveness through a paradigm shift from charity to investment, from sympathy to rights and from exclusion to inclusion are closely related; the persistent approach towards disability as a form of charity may perpetuate a lack of investment, and a lack of inclusion will reinforce inequality in society.

Therefore, regardless of individual differences, it is necessary to search for the best in people, for the benefit of society and the world around them. This is possible only through shifting the paradigm. Accepting human diversity and investing in the human capital formation of people with disabilities will strengthen the capacity of individuals to realize their positive potential, which they can use to contribute in society. We need to encourage the dream of improving the quality of life of each individual, irrespective of any impairments. The essence of this approach assumes that every individual has untapped rich and inspiring resources of skills, abilities, knowledge and experiences, which can be capitalized for the entire society by first making an effort to formulate their human capital and then obtaining multifaceted returns from the investment on the socio-economic front.

However, as poverty and inequality among and within countries persist, achieving development that includes vulnerable or marginalized peoples (including people with disabilities) remains a colossal task that requires a paradigm shift in social attitudes and strong political will. Development cannot be inclusive if it fails to enhance people's well-being by building the foundation for equality of opportunity for all strata of society, with particular focus on the poor and vulnerable who are excluded and marginalized from