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THEORETICAL AND PRACTICAL CHALLENGES OF ASSESSING DISABILITIES IN ETHIOPIA

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ABSTRACT

This paper deals with three issues in relation to disability. First, western approaches to disability particularly the medical and social models are briefly introduced. Next to this, the issue of disability in terms of demography, beliefs, culture and traditions in Ethiopia are explained. Finally the last topic deals with traditional medical practices and the challenges to study disability in Ethiopia. The way people conceive disability varied across cultures due to the social meanings attached with it. This is because of the belief system and cultural values of the people shape the perception of disability. The question is how we can assess disability through taking theoretical models which are imported from other cultural settings where people have different perceptions of disability. Such mismatch between what is in the theories and what is in the ground level makes the assessment difficult. In this scenario examining the cultural context or society's way of living is very important to assess and understand disability. Therefore, in order to operationalize the scenario and develop valid assessment techniques, the socio-cultural standards of the society on disability must be studied first. This is because "one size does not fit all."

Key words: Challenges, Assessing disability, Imported, Operationalize, Techniques

Introduction

Background Theories on the issue of disability

Traditionally, in the International Classification of Functioning (ICF) disability and health of the World Health Organization (WHO, 2001) has made two disability theories, i.e. 'medical

model' and 'the social model'. In the early years of disability studies, the medical model with its historical roots of medicine has been used as a foundation for the definition and the concept of disability. The medical model defines disability as a medical incapacity, which can be prevented, diagnosed and treated medically. If you treat the problem medically the problem will be resolved. This is based on the assumption that disability is an individual 'problem'.

Currently, this model is perceived as quite negative that doesn't fulfil needs and interests of disabled people. The new disability studies challenge the idea that disability is biologically determined, or that it is a property of individuals (Thomas, 1999). Since 1970s, this way of thinking about disability has fallen under sharp criticism from members of the disability right movement (Oliver, 1990). The movement shifted from focus on something being wrong with an individual, to the difficulties created by society. The problem of disability is therefore not with the individual, but with society and 'then the issue of interpretation of disability moves from health to human right' (Groce, 1999). The social model of disability emphasizes the promotion of social change to incorporate persons with disabilities in the larger social context. The model affirms that disability is not only medical issue but the societal restrictions emerging from discrimination.

Taking the above theory as a benchmark, the International Classification of Functioning disability and health known as ICF (WHO, 2001), views disability as problems in bodily functions or structure, problems related to activities, and problems related to social participation. The ICF defines disability as the outcomes of the interaction between a persons' heath condition and the context in which the persons find themselves. The context includes both factors external (environmental) to the person and those internal to the person (age, sex, education and skill level, coping style, and personality).

Currently, it has been estimated that about 10% of the world's population is with disability (Global Survey on Disability and HIV/AIDS, 2004). According to this estimate there are about 600 million people with different types of disabilities in the world of which 80% live in developing countries.

Situation of persons with disabilities in Ethiopia

Making the World Health Organization (WHO) and International Labour Organization (ILO) definition on disability as a standard, the government of Ethiopia defines disability as follows: 'Disability is a state in which functional limitations and/or impairments are

causative factors of the existing difficulties in performing one or more activities which (in accordance with the subjects age, sex, and normative social roles) are generally accepted as essential, basic components of daily living, such as self care, social relations and economic activity.' (Japan International Cooperation Agency [JICA], 2002). Within developing countries such as Ethiopia, data on disability rates are more fragmented and less reliable. According to the 1994 National Population and Housing Census (NPHC) 1.9% of the population are disabled but this is considered to be an underestimated. A base line survey by Tirussew, Savollainan, Agdew, & Daniel (1995) gave higher estimate of 2.9% while the survey of International Labour Organization (ILO,2003) estimated 7.6% or five million people were disabled.

Until the recent years, the number of persons with disability and their type was not well known in Ethiopia. However, according to NPHC (1994), the number of persons with disabilities constitute 1.9% of the country's total population. Among these, 19.19% constitute persons with hearing and speaking problems, 32.28% with visual impairment, 32.14% with motor disorders, 6.48% with mental problems, 3.48% with leprosy, and 6.34% were persons with other multiple disabilities.

The study by Tirusew, et al (1995) however suggests a slightly different proportion of prevalence along types of disability in Ethiopia: motor disorder (41.2%), Visual impairment (30.4%), hearing impairment (14.9%), mental retardation (6.5%), speech and language disorder (2.4%), multiple disorder (2%), and behavioural disorder (2%).

Such data show that there are inconsistencies in disability incidence estimates in Ethiopia and information available on their situation is limited. There is a lack of accurate information about the magnitude and type of disabilities as well as their causes and consequences (Federal Democratic Republic of Ethiopia Rehabilitation Agency (FDRERA) and Central Statistics Agency (CSA,1996). This may be due to two major reasons. First, the definition of disability is not clear in the Ethiopian context. Second, getting accurate information on the number of persons with disabilities is difficult since there is no regular system of recording citizens with disability and related information.

Cultural insights of disability in Ethiopia

The disability related perception of the Ethiopian society has derived from the religious and social background of the community. According to the data of Population Census Commission (2008), 43% of the total population were orthodox Christians, and 33.9%

Muslims. Protestant and traditional religious groups accounted for 18.6% and 2.6% of the population respectively. These figures seem to suggest that Ethiopians are firm believers in the power of God/Allah in directing their daily lives. They believe that the divine power has an ability to forgive and punish and do whatever it wants.

Ethiopians' beliefs/attitude about disability, therefore, heavily related to their religious doctrine that they believe in. Many people believe that those who live their lives based on the rule of their religion can live their life peacefully. But those who did wrong or sin acts will be punished. For example, in some areas people believe that children are born disabled or deformed because their parents did something bad or displeased the Gods (Colerdige, 1993). A parent who commits ill deeds, the negative effects of such past wrong doings has implications for offspring. Therefore, if a person is born disabled or something happened to him/her, it is considered God's anger on him/her and his or her family.

Zhang & Bennett (2001) suggest that religions (as well as different people within each religion) have inconsistent approaches to disabilities ranging from acceptance of people with disabilities as gifts from God(s) and therefore special, to rejection of those with disabilities as punishment from God(s).

Other people believe that God makes a person disabled purposefully (e.g. one eyed) and one day the disabled person may become advantageous. And these people always say everything that God did and has its own purpose. Here is a story:-

> *One day a person who lost his two fingers was travelling to far through valleys and forests. Accidentally, in the middle of the forest three people took him and tied him up, he couldn't escape from them. They took him to the devil (witch) who ordered the three persons to bring and scarify a man with his life and burn his body. After a long travel they reached the place where the witch was found. Then, they took off the person's cloths but when the witch observed the person's naked body he realized that the person has eight fingers, and then the witch said let this person go and find another person without defect in his body.*

Being saved from the fire, the person said 'forgive me God, for I blamed you unknowingly with my fingers. I now realized that you did it for good'.

In some parts of Ethiopia large number of people also believed that disability is the result of contact with evil spirits or evil eye (*Buda*). These thoughts in most cases related to mental illness (e.g. *Zar or Wiqabi*). *Zar* is the name of a condition and the person with this syndrome called '*Bale-Zar"or 'Bale-Wiqabi'*. The behavioural manifestation of the sprit in the

possessed person is also termed *Zar* and the behavioural characteristics are shouting with a louder voice, laughing, hitting the head against a wall, scratching a floor, crippling like a baby, eating rubbish things and etc. People believed that these things can happen when a person fail to sacrify to the sorcerer that he/she told to bring or do something before, then the spirit that the person believes in becomes angry at the person and punishes the person. These episodes are generally brief and are not considered pathological in Ethiopia and the East African countries where *Zar* is known to occur (Abebaw 2010). While disability is found in all cultures, there is a considerable variation in how cultures interpret and address disability.

There is wide spread fear and misunderstanding of disability in many societies. For instance, many people in Ethiopia do not realize that mental illness and leprosy can be treated. There is also a belief that cure is not possible -'once a leper always a leper' (Tekle-Haimanot, 1991). Such kind of thought may also cause late direct reporting of the problem to modern heath institutions (Amenu, Tefera & Byass, 2000) and inaccurate information and statistics on disability.

In many parts of the country the name the society gave to the leper was called *Kommata,* literally meaning cursed. The family of the leper person is also called a cursed family and no one of 'able bodied' had interest to have marriage relationship with a family with a leper person. In addition the societies express their perception and attitude towards disability through proverbs. Some of them are:-

- For a leper one figure is a big deal.
- A man, who had been blind for many years, when told that he will see tomorrow, said "how do I spend the night?"
- If a blind leads another blind they both go into a hole.
- In a country of the blind a man with an eye is astonishing.
- In the house of a leper one finger is big deal.
- Unless you tell a leper that he is a leper, he would eat with you.
- A crippled man always dreams to travel to Jerusalem.
- Healing a crippled person is as hard as chewing a stone.
- A church with a crippled man and a sea with crocodile won't have a peaceful night.

These proverbs show the negative attitude and beliefs of the society towards disability. A study by Tirusew (2005) on different disabilities in Ethiopia shows the expressions about disability causes stigmatization of people with disability. Some Amharic words (Amharic is the federal the working language of the country) with their literal meanings are:-

- Deafness- literally means he/she who can't understand.
- The word for blindness- literally means one who is disorganized and not bright.
- The word for physically impaired- literally means highly disfigured or mutilated.
- Intellectually disabled are called –literally means possessed by evil spirit.

All the above proverbs and meanings attached to disability show the social and cultural perception of the society towards disability and the negative connotation towards disability.

According to Tirusew both men and women with disabilities in Ethiopia face challenges throughout their lives. The traditional gender inequality makes these challenges for women and girls with disability even worse. Girls with disability are restricted in their social movement excluded from participation in community life, sexually abused, and forced to spend most of their time doing hard labour and house-hold chores.

By and large, people with disability are not welcome in society. Most people say they have the works of the bad sprit, punishment of God, and penalty of witch. Society's belief and attitudes interweave with these thoughts that lead to a child who has a disability and then consider their child as a burden. In most places of the country, families hide their child for fear of being in outcast on the village. They would not consider them as useful to the community. This may show stigma and discrimination are common reactions towards disability.

Traditional medical practices

In Ethiopia nearly 80% of the population depend on traditional medicine due to the cultural acceptability of healers and local pharmacopoeias, and the relatively low cost of traditional medicine and difficult access to modern heath facilities (Kebede, Alemayehu, Binyam & Yunis, 2006). The name of traditional practitioners varies from place to place depending on the communities where they practice including herbalists (*Kitel betash*), witch doctor (*Debtra*) and spiritual healers such as *Balewiqabiy, Qalicha and Tenquay.*

Based on their beliefs spiritual healers are grouped into two. According to the findings of (Kebede, et al, 2006) the first one is a healing practice done by Orthodox Christian clergy called *Debteras* and members of the Muslim community known as *Qalicha*. *Debteras* usually consider mental disorders as possession by evil spirits which are thus treated by praying and eventually exercising the evil spirit. Furthermore, by means of '*Digimit'* the *Debteras* claim to have the ability to perform miracles which are believed to be manifested by the reactions of their patients. Persons with disability or a family with a desirable person also go to *Tsebel*

(holy water) because there is a belief that disability is caused by evil eye, evil word and evil spirit. Therefore, *Tsebel* is believed to avoid evil spirits from patients.

The second one is *Kalicha* (a person who has spiritual knowledge in a Muslim community), people believe that *Kalicha* have an ability to investigate the cause of the problems, and they can cure disability and what will happen in the life of the individual. For instance, mental problems are generally explained as resulting from disturbance in the relationship between people and divinity (Kebede, et al 2006).

In a country like Ethiopia where there are only 4000 medical doctors for 80 million people, traditional healers are playing a significant role in the community. That is why nearly 80% of the population use traditional medicine. The cultural acceptability of the healers, and local pharmacopoeias coupled with the relatively low cost of traditional medicine and difficulty to access modern health facilities justify the wide use of traditional healers.

A study of Amenu, Tamiru & Byass (2000) on patterns of health seeking behaviour amongst leprosy patients, explained the causes of late direct reporting to modern health institutions due to high proportion of people going to traditional healers (nearly 65-80%) such as holy-water, spiritual healers, or herbalists. This is due to very low health coverage in the country with less than 45% of the population living within an acceptable distance of modern health care institutions (Ministry of Health [MOH], 1995). Either for the good or the bad nearly 80% of the population rests on the hand of traditional medical practitioners.

The question is how could these cultural beliefs, assets and attitudes be transformed from a challenge to an asset through improving the more efficacious and safe components of cultural and traditional practices. This is the challenge or the gap between the western culture (Europe and North America) and the non-western culture (like Ethiopian culture). So an understanding of these socio-cultural differences can be vital for both groups.

Theoretical and practical challenges of assessing developmental disabilities

Contrasting ways of thinking about disability have been developed more formally in the disability studies literature as the two competitive models exist. The individual model based on the assumption that the individual is the target of the problem and the social model assumes that disability is a social problem, because what stops the individual disabled person from contributing is the attitude of 'non-disabled' person towards him or her. The two models of disability are therefore the key to understanding the development of disability studies on its northern context (Schneider, 2006).

These two theoretical models which are mentioned earlier from Europe and America have been used as a foundation for disability definition, intervention and prevention to the rest of the world or majority of the world. That is why most western societies and particularly professionals presume that their biomedical and social perceptions of disability are universal concepts to understand and study disability. They ignore the majority world's cultural perceptions of disability, causation and response of the society.

Theories of disability have been developed based on the political, economic, social, and cultural deprivations encountered by disabled people in Europe and America. Applying western ideas about impairment and disability to non western cultures is fraught with difficulty (Milles, 2006). There is a considerable anthropological evidence demonstrating how social responses to the body and concept of health and ability different markedly over time and in different cultural contexts and location (Sheerd & Groce, 1988).

How Africans particularly Ethiopians perceive disability may not be the same with the exporter of the theory due to variation in geographical location, economy, culture, belief and value system. For example, Ethiopian families tend to be quite extended in which uncles, aunts, grandparents, god mothers and god fathers are considered as close family members and are often considered surrogate parents who may also contribute to nurturing and rearing of children.

The researcher's point here is that the way disability is perceived in a collectivist society may not be the same with the view and perception of an individualistic society where the theories are derived from. What is normal in Ethiopia may not be normal in Europe and America due to social and cultural meanings attached with wellbeing (health). Culture can sanction certain meanings of disability that are not known in other cultures. We even could not find an appropriate terminology to call it because-'one size does not fit all'. Although studies which are reported in the literature are sometimes carried out with or in consultation with local professionals, the interpretation of data cannot escape the inevitable influence of western culture (Kisanji, n.d.).

One of the difficulties of disability studies in Ethiopia is that how disability is best understood with its social, historical, economic and cultural foundations is not answered. This may lead professionals (researchers) to use western theories as a standard of measurement which may be alien to the people who live with disability in Ethiopia. Therefore, it is important to raise the question of transferability of 'international' models and theories to Ethiopian socio-cultural context. The cultural history of people who are living 'below

poverty line' and who hide a disabled person due to stigma and discrimination is different from the cultural history of people who are living on a better condition and better rehabilitation services.

According to Wirz & Hartley (1999) the challenge for the southern colleagues are to determine which lessons from the north (Europe and North America) are appropriate and how to use it. The challenge for universities in the north is to develop genuine line partnerships and actively listen to and learn from colleagues in the south. In order to study cultural barriers in transferability of knowledge form the developed world, scholars of the developing countries (like Ethiopia) should study the socio-cultural beliefs of disability of their own culture. Then, it is easy to adapt or reject theories imported from other areas and also open the room for the development of new theories through accumulation of new knowledge in the world.

The Ethiopian societies believe that there is always a spark of light within the dark room. So to have effective and useful theories of disability that takes in to account culture of the society, one should focus on the light with positive values with their cultural experiences. Parallel with this, particular caution must be taken when reviewing western literature on attitudes or literature that have been written on behalf of charitable organizations (Kisanji, n.d.) where lies the Ethiopians spiritual and cultural meaning of disability? Is it right or wrong to take 'international' definitions of disability as ones country definition? Or Are we taking the definition of the dominant culture? Or is it time to look within? The researcher presumes that these and other questions should be answered by the Ethiopian researchers in the area first and then one can simply measure disability in the Ethiopian context.

Conclusion

The issue of disability should be seen from different perspectives across cultures. People who are living in different cultures may perceive disability differently. This is because disability has been defined and was given meaning by a culture (Murphy, 1990). Therefore, theories, assumptions and thoughts should correspond to the social and cultural realities of the disabled person. In order to assess and intervene the problem, there should be a match between disability theories and realities. This is because, in developing country like Ethiopia, the concepts of disability are less well defined and somehow different.

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