

Anthropological Explorations in Disability Studies

¹TANYA VATS[†], ¹ANIL KISHORE SINHA[‡] & ²PRITI ARUN[‡]

¹Department of Anthropology, Panjab University,
Chandigarh 160014

²Department of Psychiatry, Government Medical College & Hospital,
Sector 32, Chandigarh 160047
E-mail: tani.vats08@gmail.com

KEYWORDS: Anthropology. Disability. Impairment. Culture.

ABSTRACT: A disability is defined as an impairment in presence of barriers that interact to limit the participation and involvement of an individual in society. Anthropology is the study of humanity, a capacious and rich universe that subsumes all. The contribution and engagement of anthropology in disability is rather new. This was initiated by anthropologist Ruth Benedict when she explored cross-cultural implications of epilepsy. Any impairment is a human experience and thus is of natural interest to anthropology. The societal perceptions and attitudes towards any differences often expel the individuals from the social milieu. An anthropological perspective can be useful to understand the social environment in which these behaviors are shaped. The present paper is an attempt to gauge the contribution anthropology has made to the field of disability studies.

INTRODUCTION

Anthropology is the study of being human, a discipline that embodies the spirit of understanding ‘otherness’ through the use of many of its approaches such as ethnography, and cross-cultural studies, etc., it is well known for its capacious and ever-expanding framework for understanding human nature and diversity (Rapp and Ginsburg 2010). Disability is profoundly a human experience, one that has much to do with the feeling of being distinct, and separates one from the so-called construct of being ‘normal’. People with disabilities are often labelled ‘the other,’ which somehow separates them from people who are not considered to have disabilities (Ablon, 1995).

The World Health Organization says that a disability is a human experience that stems from an interaction of an individual with any health condition with their personal and environmental factors in presence of limited social support and that it will touch

everyone at some point in their life, temporarily or permanently.

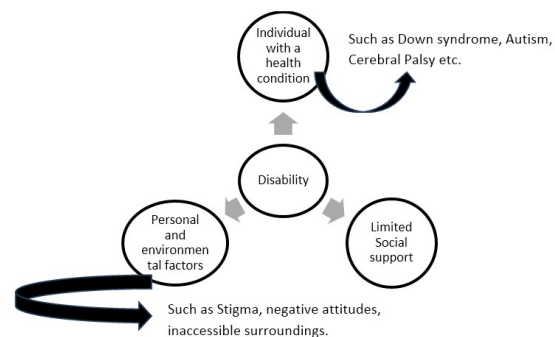


Figure 1: Pictorial representation of disability as per the World Health Organization

A disability cannot be comprehended in isolation from its social context because differences although are biologically stemmed, it is the culture and society that emphasizes and fundamentally powers these differences. Here, it is to be asserted that although disability is a universally occurring phenomenon but the responses to it are distinct and vary across the

[†] Research Scholar, corresponding author

[‡] Professor

world. What is considered to be a disability in different socio-cultural settings is highly debatable and inconsistent (Devlieger, 2018). Therefore, it is pertinent to have anthropological dialogue and engagement in the study of disability.

While talking about the concept of disability from an anthropological perspective it is important to talk about the influence of culture as the beliefs and norms of a culture influence the perceptions around disability in that society (McDermott and Herve, 1995). A disability exists when people experience discrimination based on perceived functional limitations. Depending on how societal discrimination and internalised oppression are handled, particularly the cultural and contextual ideas of cause and effect, fate, and blame, it may or may not be a handicap (Kasnitz and Shuttleworth, 2001). The recognition of disability as a social fact helps us make sense of the cultural specificities of personhood and to reconsider the unstable boundaries of the category of being human (Ginsburg and Rapp, 2020).

Anthropology and specifically medical anthropology have not ignored impairment-disability, but it is still situated peripherally to the core research issues of illness and healing (Shuttleworth and Kasnitz, 2004). The medical model of disability assumes that people with disabilities need to be corrected and cured portraying them as faulty or atypical. This can be a limitation to the discussion because of the focus on conceptions of illness and disease through a medical lens which implies a cure for people with disabilities. In this scenario, the cultural underpinnings are ignored. An alternative framework to this is the social model that considers social and cultural factors to be included in the understanding of disability and how society shapes a physiological impairment into a disability. The International Classification of Functioning (ICF) is a biopsychosocial approach of disability that merges both the medical and social models of disability. It views a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors. It asserts that disability is multidimensional and interactive and that both environmental and personal factors must be taken into consideration as they affect everything. The ICF provides a common framework for describing

the level of function of a person within their unique environment.

Disability is an alterity that is essentially a human experience. Anyone at any given point in time is susceptible to a disability because of the vulnerability of being human. It is a rather profound relational and radically contingent category that limits the full societal participation of the ones bearing it (Ginsburg and Rapp, 2020). The intersectionality of disability and the capacious horizons of anthropology make it evidently crucial to place disability in anthropological studies but despite this disability has not been in the limelight in anthropology.

INTERACTION OF ANTHROPOLOGY AND DISABILITY

Disability studies should have benefitted from anthropology's fascination and curiosity with studying otherness and the depth of the ethnographic attitude it possesses (Kasnitz, 2001; Edgerton 1984). However, whatever little anthropological interest existed was not until the late 20th century (Ginsburg and Rapp, 2020). The utilization of the magnitude of anthropological insight was very late in studying disability from an anthropological perspective and has been often seen as limited to the field of medical anthropology (Ginsburg and Rapp, 2020). However, it is anthropologists who have contributed to the understanding of disability as a socio-cultural experience and not merely a biomedical phenomenon (McDermott and Herve, 1995; Shuttleworth and Kasnitz, 2004).

The first ever dialogue about disability in anthropology was as early as 1934 by Ruth Benedict in 'Anthropology and the abnormal' when she studied epilepsy and its cross-cultural implications. She put forth that the distinctions between the categories of 'normal' and 'abnormal' are not absolute rather, they are determined by culture and what seems to be undesirable in a particular culture may be a highly valued asset in another. For the Shash tribe of California, epileptic seizures were a sign of shamanic authority and not some disdain attributed to them. Following a similar trajectory, Jane and Lucien Hanks (1948) too recognised the cultural exigency in studying a disability by recognising how a physiologically similar difference such as a scar might

be recognised differently in different cultural settings.

These studies asserted that there's a requirement for a cultural context while examining disability in anthropology and that culture is determinative of a biological diagnosis. Thus, implying that the responses to certain disabilities are not natural but rather concocted, varying among cultures. Later, Margaret Mead (1953) proposed to involve people with disabilities within the domain of all Americans while studying American national character during World War II.

Disabling conditions are stigmatizing to the extent that they evoke negative or punitive responses (Susman, 1994) and exclusion of individuals from the mainstream. The term 'stigma' refers to any persistent trait of an individual or group which evokes negative or punitive responses. Erving Goffman (1963) defined stigma as an "attribute that is deeply discrediting". He described stigma as a result of deviance. Any person who is associated with a stigmatising condition is discredited in society and because disability strays away from the norms of normalcy and invokes stigma, it thus becomes an intriguing lens through which anthropologists understand differences.

Robert Edgerton's (1967) seminal work titled 'Cloak of competence: Stigma in the lives of the mentally retarded' was an empathetic endeavour to comprehend the lives of persons classified as 'mentally retarded'. He realised the importance of anthropology in studying disability and was the first to explore mental retardation from an anthropological perspective (Klotz, 2003; Cunningham, 2009).

Based on the everyday lives of previously institutionalized people with mental retardation, he laid out how people adapted to living in the mainstream after being away in asylums and how they counteracted stigma in their lives. Edgerton argued that such individuals attempted to avoid stigma and 'pass' as normal by developing a 'cloak of competence' that is, a cluster of strategies that masked their disabilities with varying degrees of success (McKearny and Zoanni, 2018). It wasn't until Robert Edgerton's work that anthropology started to seriously pay attention to people with cognitive, behavioural, and physical impairments (Shuttleworth and Kasnitz, 2004). This was thus a ground-breaking ethnographic work that paved way for making disability a focus of

anthropological research through the use of anthropological concepts.

Gelya Frank (2000) brought another revolution by introducing phenomenological enquiry into studying disability. She wrote 'Venus on wheels' based on the life of a congenital amputee who was born without legs or arms. By far the studies focussed on outsider descriptions but this portrayal provided an 'emic' perspective by introducing subjective experiences and highlighted the need for bringing in perspectives from the point of view of the person experiencing the disability. She spent decades working with DeVries and emphasized on the reflexive role she took on during the research. Frank dwelled on how working with DeVries changed her perception of her own life. She documents her transformation from participant to friend and fellow professional as she follows the relationship's progression. Frank's decades of ethnographic interviewing with Diane DeVries and her tireless presentation broadened the scope of anthropology's interest and made it more inclusive by calling for involving people with disabilities in anthropological enquiry (Cunningham, 2009).

Joan Ablon made a significant contribution to the development of the anthropology of impairment/disability and the use of anthropology in disability research. Through her research on a variety of topics such as dwarfism, neurofibromatosis, alcoholism, and osteogenesis imperfecta she highlighted the social implications of stigmatization. Her approach helped make medical anthropology shift from a disease framework of disability toward an ethnographic focus. In her ethnographic research, Ablon documents her informants' perceptions of their bodily differences and social responses to those differences, always with an eye to reveal social injustices (Shuttleworth and Kasnitz, 2004).

Nora Ellen Groce (1985) studied individuals on an island called Martha's Vineyard in Massachusetts where hereditary deafness was so common that people didn't see it as a disability. In Groce's own words "For many generations on Martha's vineyard's deafness was no bar to a full social life" (Groce, 1985). People acquired knowledge of both English and sign language from early childhood. Sign language on the island is a part of day-to-day routine and activities

for all locals thus enabling participation in public life and therefore was not a disabling experience for the population. Karen Nakamura also worked on deaf people in Japan based on which she wrote 'Deaf in Japan' (2006), a ground-breaking study of deaf people their identity. She makes use of ethnographic research and in-depth interviews with deaf men and women spanning three generations.

Some scholars also prefer to analyse these human differences through the lens of the concept of liminality. As Victor Turner (1969) defines it, "liminal states are neither here nor there, they are betwixt and between the positions assigned by law, custom, convention and ceremonial". Therefore, it is the transition between social roles and statuses and the ambiguity that may be associated with role or status change (Cunningham, 2009).

When analysing the stigmatisation of people who have become disabled, anthropologists frequently draw on the theory of liminality. It was Robert Murphy who described the process of his paralysis because of a spinal tumor in his famous book titled 'The body silent', as a series of liminality rituals, which stripped him of his social status as and when he continued to be grappled by the severity of his condition and more disabled in the eyes of the culture. He designates physically disabled people as 'undefined, ambiguous people saying that they were in between dominant American understandings of normality: 'neither sick nor well, neither dead nor fully alive, neither in society nor wholly in it' (Murphy, 1995).

He continues by saying that people like him are resented because they are subverters of an American Ideal just as the poor because they betray the American Dream and because such people depart from the ideal, they are seen as ugly and repulsive by the able-bodied (Ingstad and Whyte, 1995). Therefore, it is the perception of them as deviant and obstructive to the community norms is what disabled them. This deviation from prevalent societal norms is referred to as deviance which Goffman had explained when he talked about stigma. He elucidated that stigma is best explained by reference to the notion of deviance and that it is not an inherent property and, in effect, a person is not a deviant until his acts or attributes are perceived as negatively different. By taking a stigma/

deviance approach, Goffman established that it is not the loss of functional limitations which constitute the greatest problems faced by disabled individuals, but rather societal and social responses to it (Susman, 1994).

CONCLUSION

Anthropology in the west has made significant contributions to understanding disability and has been pertinent in establishing the cultural connotations of the disability experience. Anthropologists have been successful in determining that disability as a category is fundamentally socially constructed and that it is not an impairment that creates a disability but rather the incompatibility of impaired bodies with social norms and material environments that are determined by the able-bodied majority and the discrimination that follows (Devlieger, 2018). Physiological differences and loss of functionality are not as limiting to the individual as the societal judgment and prejudices, that actually disable one.

There is a need for continuing emphasis on the cultural and social constructions of disability to understand how people approach and fabricate disability around them and who better than anthropologists to delve into this. For a more enriched and comprehensive understanding of human behavior in varied settings, anthropological concepts of emic and etic, stigma and liminality are highly relevant. The usefulness of anthropological lenses such as ethnography has been widely established and thus it is also a valuable tool for understanding disability. Therefore, this engagement is mutually beneficial to both anthropology and disability studies.

ACKNOWLEDGEMENT

The corresponding author (TV) is recipient of ICSSR Doctoral Fellowship and is thankful for their support. The authors are responsible for the facts stated, opinions expressed and the conclusions drawn.

REFERENCES CITED

- Ablon, J. 1995. "The elephant man" as "self" and "other": The psychosocial costs of a misdiagnosis. *Social Science and Medicine*, 40: 1481-1489.

- Benedict, R. 1934. Anthropology and the abnormal. *The Journal of General Psychiatry*, 10:59-80.
- Edgerton, Robert B. 1967. *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded*. CA: University of California Press: Berkeley.
- Devlieger, C. 2018. *Disability*. In: F. Stein, S. Lazar, M. Candea, H. Diemberger, J. Robbins, A. Sanchez and R. Stasch (eds.), *Cambridge Encyclopedia of Anthropology*. pp 1-18. University of Cambridge: Cambridge, UK.
- Frank, G. 2000. *Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America*. CA: University of California Press: Berkeley.
- Ginsburg, F. and Rayna Rapp 2020. Disability/anthropology: Rethinking the parameters of the human: An introduction to supplement 21. *Current Anthropology*, 61 (S21):4-15.
- Goffman, E. 1963. *Stigma: Notes on Management of Spoiled Identity*. Prentice Hall: Englewood Cliffs, NJ.
- Groce, N. E. 1985. *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard*. MA: Harvard University Press: Cambridge.
- Hanks, J. and Lucien Hanks 1948. The physically handicapped in certain non-occidental cultures. *Journal of Social Issues*, 4(4):11-20.
- Ingstad, B. and Susan R. Whyte 1995. *Disability and Culture*. CA: University of California Press: Berkeley.
- Kasnitz D. and Russell P Shuttleworth 2001. Anthropology in disability studies. *Disability Studies Quarterly*, 21(3): 2-17.
- Klotz, J. 2003. *The culture concept: Anthropology, disability studies and intellectual disability*. Paper presented at the Disability at the Cutting Edge: A colloquium to examine the impact on theory, research and professional practice University of Technology, Disability Studies and Research Institute (DSARI), Sydney, 12 September.
- McDermott, R. and Varenne Herve 1995. Culture as disability. *Anthropology and Education Quarterly*, 26(3): 324-348.
- McKearney, P. and Tyler Zoanni 2018. Introduction: For an anthropology of cognitive disability. *The Cambridge Journal of Anthropology*, 36(1):1-22.
- Mead, M. 1953. National character. In: A. L. Kroeber (ed.), *Anthropology Today*, pp. 642-647. University of Chicago Press: Chicago.
- Murphy, R. 1990. *The Body Silent: An Anthropologist Embarks on the Most Challenging Journey of his Life: Into the Life of the Disabled*. W. W. Norton: New York.
- Nakamura, K. 2006. *Deaf in Japan: Signing and the Politics of Identity*. Cornell University Press: New York.
- Rapp, R. and Faye Ginsburg 2010. The human nature of disability. *American Anthropologist*, 112(4): 518.
- Cunningham, R. and Allison Ruby 2009. Anthropological theories of disability. *Journal of Human Behavior in the Social Environment* 19(1): 99-111.
- Shuttleworth, R. P. and Devva Kasnitz 2004. Stigma, community, ethnography: Joan Ablon's contribution to the anthropology of impairment-disability. *Medical Anthropology Quarterly*, 18(2): 139-161.
- Susman, J. 1994. Disability, stigma and deviance. *Social Science & Medicine*, 36(1): 15-22.
- Turner, V. 1969. Liminality and communitas. *The Ritual Process: Structure and Anti -Structure*, 94 (113): 125-130.
- Internet Links
- <https://www.who.int/health-topics/disability>
- <https://www.who.int/classifications/international-classification-of-functioning-disability-and-health>