GUEST EDITORIAL: FRAMING DISABILITY ISSUES IN LOCAL CONCEPTS AND BELIEFS

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Understanding disability in a socio-cultural context is a critically important subject that deserves serious consideration. As an anthropologist, it is always tempting to list dozens of interesting examples of the different ways in which societies have interpreted what constitutes a disability and what it means to be disabled. However, it is equally important to establish some frameworks within which such beliefs and practices can be better understood. The knowledge of traditional beliefs and practices towards disability is of vital importance if we are to plan and implement programmes for individuals with disability that will make a real difference in their lives and the lives of the communities in which they live. Such knowledge can help establish what is universally true about disability and what is unique to specific cultures. When specific cultures have positive practices these may provide models for more universal approaches to disability. When specific cultures have negative practices, change may be more effectively advocated when local people come to understand that their particular opinions and practices are not found world-wide.

This paper discusses three issues in particular that must be taken into consideration as part of the evolving discussion of disability in a cross-cultural context. The first concerns seeing socially constructed concepts and beliefs about disability as ideas and attitudes that are often and increasingly in transition and not as static conceptual frameworks. The second issue deals with determining the best methodology to understand disability in the individual, family, community and societal setting out of the many methodologies that can be employed in these situations. The point here is improving communication between these methodologies. The third issue is about ensuring that the information gathered is disseminated broadly, which means sharing the information generated not only with those interested in disability issues, but also with those working on issues such as development policy, social change and justice, who know little about disability. In both the industrialised and non-industrialised world, disability issues must be brought to the attention of individuals and organisations that are currently unaware of how deeply their policies and programmes affect the lives and well-being of those with disability.

There is an increasing awareness of the importance of understanding traditional beliefs, attitudes and practices towards disability (1). Culturally imbedded conceptual frameworks of disability affect the way in which individuals with disability see themselves and the world around them (2,3). They effect the way in which people in their world, such as members of their family, their community, and their society, interact with them (4,5), and they are the basis on which societies implement policies and programmes that directly and indirectly affect their right to play meaningful roles in their communities. These beliefs are not always negative. But whether positive or negative, it is necessary to understand them in order to effect change, either by addressing the negative models or by building on positive traditional models.

Discussion about disability, even in the established western-based literature, is too often mired in sweeping stereotypes that provide relatively little information at the individual or the community level. In fact, `disability' as a concept, is rarely found in most traditional societies. Rather, societies around the world have tended to group together individuals with specific types of disability, such as 'the blind' or 'the deaf', and often have specific and very different ways of responding to individuals depending on what type of disability they have (6). Although traditionally there may be broad categories such as 'the unfortunate', 'the infirm' and so on, the idea of disability as a broad category into which individuals with a diversity of physical, emotional and intellectual impairments are placed, is of relatively recent origin. It seems to be a by-product of broad social insurance and social security schemes that have grouped these previously distinct categories of individual experiences together in order to provide benefit packages within nation states (7). This collapse of culturally distinct categories, which has become common during the past 50 years, has influenced many of our initial attempts to look at disability cross-culturally.

In fact, across cultures traditionally, individuals seem to have been categorised and their place in society determined by a number of variables concurrently, rather than by one variable such as the presence of an impairment. The type of impairment an individual has is among the most prominent of these variables. In almost all societies certain types of disability are far more acceptable than others (2). The acceptability of different types of disabilities do not seem, in a cross-cultural context to be determined arbitrarily, but seem to be closely tied to how a society explains the appearance of that specific kind of disability. For example, in a society where it is believed that mental retardation happens by chance, but blindness is caused by sorcery, an individual with mental retardation may be easily integrated into the community but a blind person will be avoided by everyone.

Secondly, an individual with a disability is affected by what the social expectations are for such individuals when they reach adulthood. For example, in societies such as some in Oceania or New Guinea where oration or the ability to speak eloquently and persuasively in public forums, is the way in which men gain power and prestige within the community, men with speech problems, hearing problems or intellectual impairments, will be at a particular disadvantage. Women with similar impairments or men and women with other types of impairments, may not face as severe social isolation or community discrimination (8). In societies in which most adults must engage in substantial amounts of physical labour in fields, individuals with mobility impairments may be at a distinct disadvantage (1). This does not mean that individuals with other types of disabilities, for example, deafness, do not encounter difficulties as well. It is only that certain types of impairments are considered particularly disabling when compared to others (9,10). In studies where western researchers seek to determine the social status of all individuals with 'disabilities', the difference in social expectation for one who is blind verses one who is mobility impaired, may be missed. However, in the real world, the need to understand where an individual with a specific impairment is located within a complex socio-cultural framework, is essential if viable programmes are to be established.

Another problem in the cross-cultural study of disability is the tendency to make sweeping generalisations about all individuals with a disability in a specific culture. Cultural beliefs are important to understand, as they provide an overview of beliefs and attitudes towards individuals with disability, but no individual lives in a culture. An individual lives within a social network, a matrix of family, friends and community. As such, there are a number of variables that must be taken into consideration when discussing individuals with disability in any society.

These variables include what group within the greater society an individual with disability belongs to; the socio-economic status of the family into which an individual is born; the gender of the individual and the specific socio-cultural roles and rights linked to gender, his tribal affiliation, caste or class group, what region the individual comes from and so on. To this must be added the variables of who the person with disability is as an individual, his or her level of education, chosen profession, marital status, and so forth, which will also make some difference in how he or she fares within the traditional cultural matrix. For example, if a poor widowed washerwoman with several children, living in the slums of Mexico City loses her vision, her lot in life may become exceptionally difficult. Even if her family can provide some assistance, the chances are that she and her family will struggle to meet their basic needs. If the wife of a prosperous local merchant, living a few miles away, loses her vision from an identical cause, her prospects for the future will be markedly different. This woman and her family will probably hire help to assist her in fulfilling her daily responsibilities as a wife and mother and to ensure that she is able to go where she wishes and do the things that she finds enjoyable. It is unlikely that she and her family will have to struggle for survival from day to day. The prevailing social beliefs about blindness may affect both women equally. However, the variables of class, marital status and economic stability will make an enormous difference in the choices each will have as they deal with their disability. Such expectations may be based on social expectation, not only of societal groups, but also of specific families and subgroups. For example, in the United States, it has been noted that many parents who are well educated and who expect their children to go to college, have more difficulty accepting a child with mental retardation than one with a mobility impairment (11).

In studying traditional beliefs and practices, care must also be taken to ensure that socio-cultural belief systems are not viewed as 'static', remaining more or less unaltered through time. While many traditions and beliefs about disability are exceptionally long-standing and are intricately interwoven into many aspects of the local cultural belief system (6), it is important to understand that belief systems change over time, and that often belief systems change rapidly when traditional systems intersect with western ideas and rapidly modernising national and regional trends (12). Increasingly, people on all continents have some exposure to radios, televisions, movies, magazines and newspapers. Today we can fax Easter Island or e-mail New Guinea from our own homes, and friends and colleagues can phone us from northern Thailand or central Sri Lanka.

We must think more creatively about how attitudes, understanding and beliefs change under the impact of this increasingly rapid flow of information. Unfortunately, much of the current discussion of attitude change hypothesised for disability assumes a rather simplistic model for change. Although models such as Community Based Rehabilitation (CBR) focus on community oriented change, for many international development agencies and national governments in the developing world, the assumption all too frequently, is that disability beliefs will move from traditional attitudes and practices to a western based charity or medical model. In such a model, professionals from medicine and allied disciplines become gatekeepers to a host of largely institutionally based services; it is a system that essentially further dis-empowers and dis-enfranchises individuals with disability.

The scenario this presents is indeed daunting. Ideas which have already begun to be discredited in the industrialised world are being foisted on countries and communities in the non-industrialised world. The fact that these communities have so few resources for disability in the first place makes the prospect of spending scarce resources on high priced professionals, costly institutions and technologically sophisticated programmes, more incomprehensible. That these programmes will reach no more than a handful of individuals, usually in the capital city, is of further concern. Certainly there has been enough waste in 'top down' schemes in international health and development to give us pause, although such predictions do not give nearly enough credit to thoughtful individuals and advocacy groups in the developing world, who are often far more sophisticated about the strengths and weaknesses of western thought and modern development issues than they are given credit for.

The reality is more complex. People undergoing social change rarely abandon everything they know and everything they practice, in order to unquestioningly adopt a new system of thoughts, beliefs and behaviours. Rather, as international health and development agencies are increasingly coming to realise, new and old ideas often co-exist and frequently co-mingle, producing hybrids that are neither wholly the old nor the new system. For example, a mother of a young child with a genetically based impairment from a very traditional Italian-American family, complained bitterly to this author that her grandmother had announced right after the birth of her child that "God had cursed" the family by giving them 'bad blood'. The mother reported that she had spoken at length with the geneticists, who had assured her that 'God had cursed' the family through the genes that had been passed down through generations. During the life of this child, it will make little difference whether the family conceptualises the issue as one of 'bad blood' or of 'genetics' as long as they continue to couple the explanation with a curse from God. The geneticists would be troubled to learn that their state-of-the-art scientific explanation is being incorporated into a very traditional belief system to provide a culturally satisfactory interpretation, and that provision of a scientific explanation alone does not mean that the mother must accept it without interpreting it in her own way.

To add to the complications of how new ideas and explanations are accepted, it must be remembered that not everyone in a society will take up new ideas at the same time. There will always be a vanguard of individuals who will accept and promote new ideas, such as the need to empower and include individuals with disability. There will also always be individuals, including many policy makers, who may be more keenly interested in maintaining a status quo. Furthermore, there will also be some who waver between systems, such as those who in times of calm may give lip service to and even believe in progressive models of disability in society. When faced with the need to make decisions, particularly when it comes to prioritising scarce resources or the transfer of power from established professionals and policy makers to those with disability or those who are otherwise disenfranchised, they may return to older and more dearly held `belief' models.

The second issue to be raised here is how we can best study the complex interplay between the numerous variables that make up the lives of individuals with disabilities in a social matrix. Over the past decade, a growing literature clearly underscored the fact that there was not one way to approach disability in society, but many. The social sciences such as anthropology, sociology, political science and economics, and humanities such as history, philosophy, folklore, art, literature and language studies, have joined the long established fields of medicine, biology, psychology, rehabilitation and occupational therapy, to throw new light on what it means to live with a disability. Fields of study that combine a number of disciplinary approaches, such as public health and international health also have much to offer.

There is no single 'right' way to look at disability in society, but there is a wrong way. The wrong way is to mistake one's own disciplinary training as the sole approach to a complex problem and with an almost missionary zeal, go forth to do battle with anyone who is not conversant in the tenets and terminology of one's particular discipline. A different approach is not a less valid approach. The ongoing argument between "science" and "humanities", between "hard" and "soft" sciences or between "qualitative" and "qualitative" research, has not solved the basic problem. The problem lies in the fact that all too few people stretch beyond the boundaries of their own disciplines or frames of reference to gather insight and information from other scholars, advocates or policy makers who may be framing disability issues very differently. We do not have to fully agree, but we need to be more knowledgeable about what questions are being asked by other disciplines and what assumptions are being made, both by ourselves and by others. There is a need to think more creatively about how questions raised by other disciplines may also be of relevance to our own work.

For this reason, a discipline such as the newly emerging Disability Studies, takes on special relevance. Disability Studies, like Women's Studies or Ethnic Studies, is both a conceptual lens through which to examine a part of the human condition, and a cross-road to bring together a number of different perspectives to allow an interdisciplinary examination of a complex topic. There is a growing literature on Disability Studies (13), which is not discussed here. However, people in disability-oriented research too often end up speaking only to the disability group, "preaching to the converted", as it were.

By way of example, the field of Disability Studies might fruitfully be compared to the field of African-American Studies which has developed in the United States over the past thirty years. Beginning with a population that was not perceived to have much of a past by then-current scholars, and which was believed to lack significant documentation, a fascinating field of research has since grown. The resulting research has filled in large gaps in our knowledge of the African-American community in particular and of who we are as a nation in general. Unfortunately, many Americans remain unaware of this rich heritage, and African-American Study classes in American universities usually attract only small numbers of non-African-American participants. As is the case in African-American studies, in Disability Studies one needs to make sure that establishing separate journals, curriculum and societies does not further marginalise the issues of disability from the marketplace of ideas.

The third issue to be raised in this paper expands on the previous point of the need for taking what one is learning about disability in society beyond the bounds of his own personal and disciplinary networks. In order to make a difference, the understanding one gains about disability in society must be disseminated in a way that will affect perceptions, and ultimately policy on disability. The more one learns about disability in the context of societies and the various engendered, social and economic consequences of disability, the more important it is for one to reach fellow academics, advocacy groups, policy makers and the general public. This means writing, speaking and advocating in more arenas than simply disability-related ones. Political scientists, economists, legal and human rights advocates, all need to hear from us. If we remain silent, we give up the right to put disability on the agenda of many different groups.

For example, a particular interest of this author in recent years has been disability in international health and development. Where do individuals with disability currently fit in this arena? All too often, there is an assumption that individuals with disabilities will benefit from general programmes, such as economic development, education, transportation, and so forth, that are intended to benefit the whole community. Is it possible that they may instead be further marginalised? Is it possible that traditional roles, rights and responsibilities that individuals with disabilities have held, will be superseded in the interests of development and gain ? Do we know what we should be doing in the face of this trend to monitor changes in social and economic systems that may have such a profound effect on individuals with disability globally? If people interested in disability do not stay involved, and if they are not advocating on behalf of disability in society, they are liable to lose whatever gains they have already made. For example, the World Bank and other institutions have recently introduced a new way of calculating disability, entitled the Disability Adjusted Life Years (DALY) (14, 15). It is an economic model in which an individual with a disability is methodologically assumed to be an economic drain on a society. There is no way, according to this model, that individuals with disability can make a positive contribution to the society in which they live. The Disability Adjusted Life Years (DALY) is of particular concern because this model is designed to be used by health ministers at the local and national levels to help allocate scarce resources (16). It goes without saying that this model ignores an entire body of research and advocacy that has been developed over the past twenty years. Obviously, if individuals with disability in this model are not considered as "contributing members of society", then the amount of funds officials will be willing to allocate for education, job training, social inclusion, health services, accessible architecture, transportation systems and so on for disability, will be far less - or nothing at all.

In conclusion, understanding traditional concepts and beliefs about disability are fundamental to our understanding of how to approach systems and how to foster productive change. If change is to be brought about, we must understand what is good and can be built on, and what needs to be changed. But it must also be remembered that all societies change over time and incorporate new ideas into a cultural whole. Having said this, one can not simply list what the traditional beliefs and practices are. We need to understand beliefs, practices, customs and issues as part of a viable and interconnected set of systems that are closely linked and often evolving over time.

To understand the complexity of issues surrounding disability in society, it is important to reach beyond the boundaries of our particular disciplinary and ideological frameworks, and seek productive dialogues with others using different disciplinary approaches. Even Disability Studies can not be an end in itself. We must take what we learn in Disability Studies and integrate it into other fields of study. We may not be able to get all to agree with us or to see our point of view, but the effort must be made.

Furthermore, information on disability needs to be disseminated to a wider audience, to individuals and groups that work in areas of social, political and economic policy making that may rarely or never think in terms of disability. Where broad social change is being advocated, where projects, programmes and initiatives are underway, we need to have a voice. Throughout the world, thousands of initiatives not considered 'disability related' will nonetheless effect the lives of many with disability on a local, national, regional or global level. For those making decisions about such programmes, an awareness of disability and the ramifications of local ideas and beliefs about disability cross-culturally, is imperative.

Finally, the responsibility and choice for how this new knowledge is to be used, and what changes may be promulgated or what traditional ideas and practices are to be kept must ultimately rest with the individuals with disabilities within their respective societies. Disability issues are human rights issues. The more we can understand about the local concepts and beliefs about disability in different cultures, the more we can ensure that individuals with disability have a voice as we move with increasing speed into the 21st century.

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