GENERAL ISSUES IN RESEARCH ON LOCAL CONCEPTS AND BELIEFS ABOUT DISABILITY

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INTRODUCTION

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 a framework within which such beliefs and practices can be better understood. Knowledge of traditional beliefs about and practices towards disability is of vital importance in order to plan and implement programs 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.

In the following paper, I will discuss three issues in particular that I believe must be taken into consideration as part of the evolving discussion of disability in a cross-cultural context. These are:

1. Seeing socially constructed concepts and beliefs about disability not as static conceptual frameworks but rather as ideas and attitudes that are often (and increasingly) in transition;
2. Determining what methodology is best to understand disability in the individual, the family, the community and society (I will argue there is not one, but many methodologies that can be employed – the issue at this point, is communication between these methodologies); and
3. Ensuring that the information gathered is disseminated broadly. This means sharing the information being generated not only with those interested in disability, but just as importantly, with those working on broad social policy and social justice issues who currently know little about disability. In both the industrialized and non-industrial-

ized world, a better job must be done of bringing disability issues to the attention of individuals and organizations that are currently unaware of how often and how deeply their policies directly effect the lives of people with disability.

BACKGROUND

There is an increasing awareness of the importance of understanding traditional beliefs, attitudes and practices pertaining to disability (Mallory 1993). Culturally imbedded conceptual frameworks of disability affect the way in which individuals with disability see themselves and the world around them (Scheer/Groce 1988; Helander 1993). They affect the way in which people in their worlds – members of their families and their communities – interact with them (Groce 1990; Ingstad/Whyte 1995), and they are the basis upon which societies implement policies and programs that directly and indirectly affect all aspects of their lives. These conceptual frameworks of disability are not always negative. But whether positive or negative, it is necessary to understand traditional models in order to effect change, either by addressing negative models or by building upon positive ones.

GENERALIZATIONS ABOUT DISABILITY CROSS-CULTURALLY

Discussion of disability in society, even in the extensive professional literature, is too often mired in sweeping stereotypes that provide relatively little information about disability at the individual or the community level. In fact, *disability* as a single concept is rarely found in most traditional societies. Rather, societies around the world have tended to group together individuals with specific types of impairments (i.e. *the blind*, *the deaf*), and often have very different ways of responding to individuals depending on what kind of social interpretation underlies their specific disability. Although traditionally there may be broad categories (i.e. *the unfortunate*, *the infirm*), the idea of disability as a single category into which individuals with all types of physical, emotional and intellectual impairments are routinely placed, is relatively recent. It seems to be a byproduct of broad social insurance and social security schemes that have grouped previously distinct categories of individuals together in order to provide benefit packages within nation states (Groce 1998).

This collapsing of culturally distinct categories of individuals has influenced many initial scholarly attempts to look at disability in society. In fact, looking cross-culturally, societies traditionally seem to have categorized individuals and determined their place in society using not one variable (i.e. the presence of an impairment), but by considering a number of variables simultaneously. For example, in almost all societies, certain types of disability are far more acceptable than others (Scheer/Groce 1988). The acceptability of different types of disabilities does not seem, in a cross-cultural context, to be determined arbitrarily, but rather to be closely tied to two factors:

1. How a society explains the appearance of that specific type 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 widely avoided; and
2. what the social expectations are for the individual with that type of disability when he/she reaches adulthood. For example, in societies such as some in Polynesia where oration (the ability to speak eloquently and persuasively in public forums) is the way in which men gain power and prestige, men with speech impediments, 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 significant a lack of social status (Regill/Jarrow 1993).

In communities in which most adults must engage in substantial amounts of physical labor, such as farming or fishing, individuals with mobility impairments may well be at a distinct disadvantage (Mallory 1993). This does not mean that an individual with another type of disability – for example, deafness – does not also encounter difficulties, only that certain types of impairments are considered particularly disabling (Goert 1989; Cunningham 1989). In studies where Western researchers seek to determine the status of all individuals with *disabilities*, the difference in social expectation for one who is blind versus 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 programs are to be established.

Another problem in the cross-cultural study of disability is the tendency to make sweeping generalizations about all individuals with disability within a given culture. A culture is a group of people with a shared set of beliefs and practices, which are passed down from one generation to the next. These beliefs and practices are the cornerstone upon which individuals frame their understanding of the world around them and their role within this world.

However, no individual lives in a culture; an individual lives within a society, a network of family, friends and community. As such, there are a number of variables that must be taken into consideration when discussing any specific individual with disability. These include: the socio-economic status of family into which an individual is born, the gender of the individual (and the specific socio-cultural roles and rights linked to gender), his or her tribal affiliation, caste or class group, and so forth. To this must be added the variables of individual attributes: a person's level of education, chosen profession, socio-economic status, marital status, and individual temperament. All these will also make some difference to how he or she fares within a 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. The chances are that she and her family will have to struggle to meet their basic needs. The wife of a prosperous merchant, living a few miles away, may have an identical vision loss, yet her prospects for the future will be markedly different. Household help may be hired to assist her in carrying out her responsibilities as a wife and mother and in continuing to do those activities she finds enjoyable. It is unlikely that her vision loss will affect her family's ability to obtain food or housing. While the prevailing social beliefs about blindness may affect both women equally, variables of class, marital status and socio-economic stability will make an enormous difference in the choices each will have as they deal with their disability. Response to an individual's disability will be based not only on broad traditional beliefs, but also on the social expectations. For example, in the United States, it has been noted that many well educated parents who expect their children to go to college have more difficulty accepting a child with mental retardation than a child with a mobility impairment (Groce/Zola 1993).

CHANGE OVER TIME

In studying traditional beliefs and practices, care must also be taken to ensure that socio-cultural practices and beliefs are not viewed as static (remaining more or less unaltered through time). While beliefs about disability are often exceptionally long-standing and intricately woven into many other aspects of the traditional culture (Groce 1998), it is important to be aware that belief systems can change over time. Often beliefs change rapidly when traditional systems intersect with Western ideas and rapidly modernizing national and global trends (Barnartt 1992). Increasingly, people on all continents have some exposure to radio, television, movies, magazines and newspapers. Today one can e-mail New Guinea from an office in London or make a cellular phone call from Gabon to a colleague in Cuba. For that reason, more critical and creative thinking must be done about how attitudes, understandings and beliefs change under the impact of this increasingly rapid exchange of information. Unfortunately, much of the current discussion of attitude change hypothesized for disability ignores this rapidly increasing global exchange. All too frequently, the understanding is that disability beliefs will move from traditional attitudes and practices to the Western-based medical model, in which professionals from medicine, rehabilitation and allied disciplines become gatekeepers to a host of predominantly institutionally focused services, a system that essentially disempowers and disenfranchises individuals with disability.

The scenario this presents is indeed daunting – ideas that have already begun to be discredited in the developed world being promoted in the developing world. The fact that many nations have so few resources for disability in the first place, means the prospect of expending scarce resources on professionals, costly institutions and technologically sophisticated programs causes some concern. That these programs 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 one pause, although predictions of the global dominance of Western medical models do not give nearly enough credit to thoughtful individuals and advocacy groups in the developing world. These experts and advocates are often very sophisticated about what the strengths and weaknesses of Western models are. Initiatives such Community Based Rehabilitation (CBR) also allow a much greater community voice in defining beliefs and practices relating to persons with disability. In reality, understanding changing social beliefs and practices may be very complicated. People living in rapidly changing societies or who are from traditional ethnic or minority populations within developed countries, rarely abandon everything they know and practice in order to unquestioningly adopt a new system of thoughts, beliefs and behaviors. Rather, new and old ideas often co-exist and frequently co-mingle – producing hybrid belief systems that are neither wholly old or new. For example, several weeks ago I was sitting with a mother of a child with a genetically inherited impairment; the latter came from a very traditional Italian-American family. The mother complained bitterly that her own grandmother had announced immediately after the child's birth that "God had cursed the family"; that they had "bad blood". The mother earnestly said that she had spoken at length with the geneticists, who had assured her that "God had cursed" the family "through genes" that had been passed down through the generations. In the life of the child, it will make little difference whether the family understands 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, I suspect, 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. It should also be remembered that not everyone in a society will adopt new ideas simultaneously. 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 be individuals, both in the general population and in positions of power, who may be more keenly invested in maintaining a status quo. Furthermore, there will also be some who waver between systems – those who may accept progressive models of disability in society but who, when faced with the need to make decisions, may return to older and more dearly held medical or charity belief models. This may be particularly true when it comes to prioritizing scarce resources or to the transfer of power from professionals and policy makers to advocates or to those who were previously disenfranchised.

THE STUDY OF DISABILITY IN SOCIETY

The second point to be raised in this paper is the need for more and better conceptual models. How can scholars best study the complex interplay between the numerous variables that make up the lives of individuals with disabilities? Over the past decade, a growing literature clearly underscores the fact that there is not one way to approach disability in society, but many. The social sciences (anthropology, sociology, political science, economics, etc.) and the humanities (history, philosophy, folklore, art, literature, language studies and so forth) have joined the fields of medicine, biology, psychology and 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 interdisciplinary approaches, such as public health, international health and international development, and of course, disability studies, also have much to offer.

There is no single *right* way to look at disability in society – but I would argue there is a wrong way. The wrong way is to mistake one's own disciplinary training as the only approach to understanding disability. Unfortunately, some scholars, with an almost missionary zeal, go out to do battle with anyone who is not conversant with the tenets (and terminology) of their particular discipline. A different approach is not a less valid approach. The on-going argument between science and the humanities, between hard and soft science and between qualitative and quantitative research has not and will not solve the basic problem. The problem is that too many of us do not stretch beyond the boundaries of our 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. Scholars need to think creatively about how questions raised by other disciplines may be of relevance to their own work. Policy makers have much to learn from advocates. Too often people are put off by different terminology, just when they should be enlightened by new perspectives.

For this reason, a discipline such as the newly emerging field of 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-roads bringing together a number of different perspectives to allow an interdisciplinary examination of a complex topic. As there is a growing literature in the field of disability studies, it will not be discussed at great length here. However, I would like to add a note of caution. I am concerned that disability-oriented researchers may too often wind up speaking only to themselves. As a college professor, I have observed the development of a number of disciplines which, like disability studies, concentrate on one particular group within the broader population. These areas of scholarly concentration have often yielded a wealth of information and insight. For example, in the United States, the field of African-American Studies has produced a fascinating body of work, which has filled in large gaps in our understanding of the African-American community in particular and broader American history in general. Unfortunately, all too many Americans remain unaware of this rich heritage, as classes in African-American Studies in our nation's universities and scholarly books and journals on the subject often attract only a small number of students beyond the African-American community itself. Disablity studies faces the same danger of finding itself *preaching to the converted.* All disciplines need to establish an identity by fostering separate journals, curricula and professional societies, but it is important that as a discipline, disability studies should not be marginalized in the marketplace of ideas. Which leads me to my third point: dissemination of information on traditional beliefs and practices beyond personal and displinary networks.

DISSEMINATION

The more we learn about the various gendered, social and economic consequences of disability, the more important it is to reach fellow academics, advocacy groups, policy makers and the general public in a way that will improve understanding and ultimately, policy on disability. This means writing, speaking and advocating in more arenas than simply disability-related ones. Certainly, disability advocacy and scholarship remains vitally important – what is advocated here is simply to broaden the agenda further. For example, political scientists, economists, bioethicists, legal and human rights advocates and more, all need to hear from us. If disability scholars and advocates remain silent, they give up the right to bring disability *to the table.* For example, my own particular interest in recent years has been in the area of disability in international health and development. Where do individuals with disability currently fit in this arena? All too often, I think, there is an assumption that individuals with disability will benefit from general programs (economic development, education, transportation, and so forth), that are intended to benefit the whole community. Is it possible that people with disablity may instead be further marginalized? Is it possible that the traditional roles, rights and responsibilities individuals with disability have held will be abandoned or ignored in the interests of economic development or the trend from extended to more nuclear family systems? What should be done to monitor changes in local, national and global social and economic systems that may have a profound effect on individuals with disability?

Allow me to provide an example: Mary Chamie, Angela Me and I have just finished a paper (Groce/Chamie/Me forthcoming) on an issue about which we are gravely concerned. A new way of calculating disability is being forcefully advocated by economists. It is called the Disability Adjusted Life Years (DALYs) (Murry/Lopez 1994; 1996). The Disability Adjusted Life Years is an economic model in which an individual with a disability – *any disability* – is methodologically assumed to be an economic drain on society. There is no way, according to this model, that an individual with a disability can make a contribution to the society in which he or she lives (It goes without saying that this model ignores an entire body of research and advocacy that has been developed over the past twenty years). However, the DALYs are 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. Obviously, if individuals with disability in this model are not considered "contributing members of society", then the amount of funds ministers of health will be willing to allocate for their education, job training, social inclusion, health services, or accessible architecture and transportation systems, will be far less. Or nothing at all.

CONCLUSION

It is important to increase our understanding of traditional concepts and beliefs about disability. If change is to be brought about, a better understanding is needed of what aspects of traditional beliefs and practices are good (and can be built upon) and what beliefs and practices limit individuals with disability (and need to be changed). It must also be remembered that all societies change over time and incorporate new ideas into a cultural whole. Knowing this, simply listing traditional beliefs and practices relating to disability in a specific society is at best, a form of academic butterfly collecting. Such beliefs and practices must be analyzed as part of a complex and interconnected system of ideas and actions. To understand the complexity of issues surrounding disability in society, it is important to reach beyond the boundaries of particular disciplinary and/or ideological frameworks and seek productive interdisiplinary dialogue. Even disability studies can not be an end in itself. What is learned in disability studies must be brought back and integrated into other disciplines which are not explicitly disability focused. Ultimately, any discussion of history, society, literature or politics must include an awareness of disability, just as such discussions now routinely include women's issues.

The rapidly growing body of information and insight on disability in society must be disseminated to wider audiences, beyond the bounds of academics. In particular, attention must be paid to disseminating ideas and information from this rapidly emerging field to those working in social, political and economic policy and programming. Where broad social change is being advocated, where projects and programs are underway, those involved with disability issues need to have a voice. Although in many nations there are only a handful of programs that are specifically labled as *disability related*, thousands of initiatives in economics, education, development, leadership training and health will nonetheless effect the lives of millions with disability. For this reason, an awareness of disability and the ramifications of traditional beliefs and practices towards disability cross-culturally, is imperative. Disability issues are human rights issues – the more that is understood about the traditional beliefs and practices, the more individuals with disability will have a voice in our increasingly global and rapidly changing world.

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