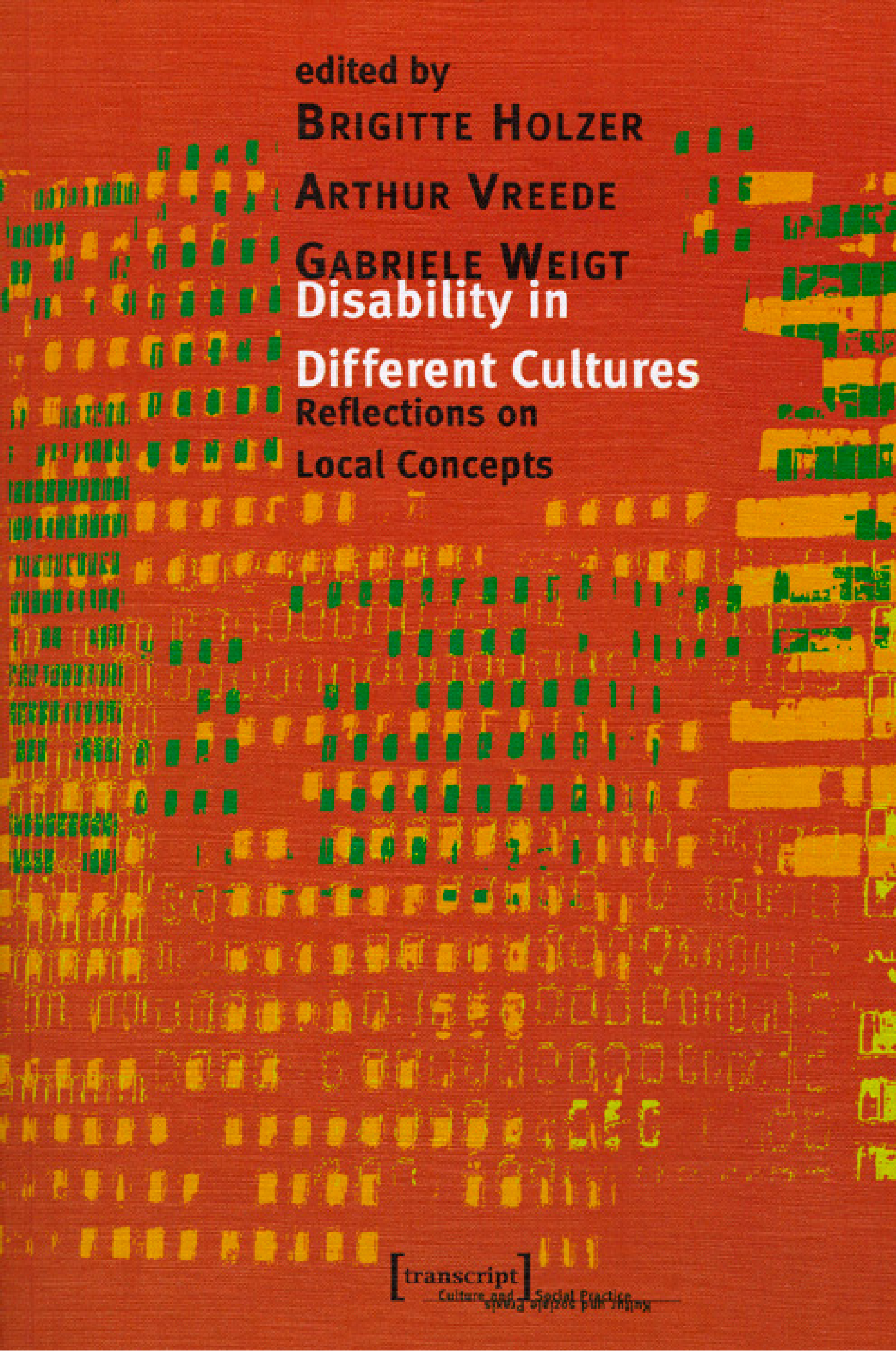

edited by

BRIGITTE HOLZER

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GABRIELE WEIGT

Disability in Different Cultures

Reflections on Local Concepts

[transcript]
Culture and Social Practice

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This book is a collection of contributions presented and discussed at the symposium “Local Concepts and Beliefs of Disability in Different Cultures” (21st to 24th May 1998), organized and coordinated by the following NGOs:

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INTRODUCTION

Brigitte Holzer, Arthur Vreede, Gabriele Weigt

There are at least three good reasons for publishing a reader on the topic of *Disability in Different Cultures*. The first is of a practical nature: this book is a collection of virtually all the contributions presented and discussed at the symposium *Local Concepts and Beliefs about Disability in Different Cultures* (21st to 24th May 1998 at the Gustav-Stresemann-Institut e.V. in Bonn, Germany). Here, people with disabilities from both North and South met with special education professionals, people working in development cooperation organisations and students and academics from different disciplines concerned with disability, and started a dialogue which is, we trust, reflected in this reader. It is the editors' hope that this dialogue, which was at most merely initiated at the symposium, can and will be continued in greater depth on the basis of this collection. The reader has the further aim of carrying the dialogue beyond the restricted circle of symposium participants and making it accessible and comprehensible to a wider public.

The second reason for the publication of this book relates to the experiences of many of those engaged in development cooperation and working in NGOs, experiences which represented an important impetus for organising the symposium and which, correspondingly, constituted the central topic of both plenary sessions and working groups. *Disability and Culture* is an essential issue in development cooperation. On the one hand, disabilities, whether physical, mental or emotional, can be seen as parameters for the structural disadvantaging and deficits of the countries with so-called *catching-up development*. They are very frequently the results of hunger, malnutrition and wars (cf. the contributions by Tietze, DeKeersmaeker and Boyce/Weera in this volume). Thus NGOs are confronted with the issue of disability, no matter what social and economic areas they are concerned with. On the other hand project planners – advisors, health educators and other socially engaged individuals – find again and again that their work cannot achieve the intended results, is unsuccessful, is avoided or even completely rejected by the people affected, or that support for a particular person ends in personal disaster, because the target group attributes different meanings to disability from the planners. This can be illustrated by the example of the Cambodian mine victim who was fitted with a prosthesis in an NGO aid programme. Some days later, the man was seen begging at the roadside, minus prosthesis. When asked why he was not wearing it, he replied: Your prostheses can't feed me (Tietze in this collection, see also the contributions by Kalyanpur and Groce). One of the aims of the reader is, therefore, to create an awareness of the gaps in our knowledge when it comes to the framework of spiritual, cultural and socio-economic conditions which affect the issue of disability in different societies, and at the same time an awareness of how to reduce this gap, or rather, how difficult it is to acquire the appropriate knowledge.

The third reason for addressing the issue of *Disability and Culture* is the most wide-reaching, even if it is the least evident at first glance, and relates to the emancipatory potential of the topic. In exploring the wide variety of local concepts of and different ideas and beliefs about disability, it becomes strikingly clear just how differently a disability may be judged. In this light, *disability* can no longer be perceived as a physical, psychological or mental characteristic which a person is born with or has acquired in the course of her or his life. On the contrary, it becomes evident to what a large degree the attitudes and the interactions with others that are usual in the respective social context form and influence the nature and extent of a disability and thereby determine the life of the disabled person. This altered consciousness with regard to disabilities makes it possible to perceive a condition formerly held to be *natural* – where the disability was seen as an inborn physical state, entailing consequences viewed as inevitable – as something which can be both changed and shaped.

Over the last three decades, people who found themselves pushed to the fringes of society (women, ethnic minorities, gays and lesbians, disabled people) have stood up for equal rights on various political levels, whilst also pressing for representation and a voice in academic writing and research. This reader aspires to make a contribution to the discourse both of and about people with disabilities and the contexts of their experience. In addition, its intercultural nature is able to show with particular clarity that a discussion of *disability* always also incorporates *non-disability*, as well as the dominant concepts of normality. By looking at different social constellations, it reveals how variously people create normality, or conversely, make differentiations and draw borders. Each conception of disability points to more comprehensive conceptions, to comprehensive social meaning structures, on whose basis for example incapacity, illness, invalidity, disfigurement, death and anomaly are differently rated and judged. A confrontation with the structures that regulate the social life of another society throws light upon the structures of one's own, which are otherwise often obscured (cf. Albrecht's contribution in this collection). Not only for people with disabilities does examining these structures make sense.

Since the 17th century at the latest, the populations of the South have been confronted with values and meaning structures alien to them, and forced to mediate between these and their own. For people from the North, this has hitherto not been necessary. The stream of exports of development aid – know-how, expertise, assistance, (special) educational concepts – flows from North to South. Conditions are attached to the aid provided, and there are frequently deliberate interventions in the social structures of the so-called beneficiaries.[1] Often however this type of influencing occurs subconsciously rather than on directly perceptible levels. As long as the flow of aid continues to take this course, then, it is important for the people of the South that those involved in development cooperation take local concepts and beliefs seriously, are interested in them, and occupy themselves with them. At the same time, such intercultural work is able to draw attention to experiences and knowledge in the field of disability which people are not (or are no longer) aware of. With reference to area of South East Asia, Miles' contribution in this collection shows just how important the history of disability and rehabilitation in one's own region or else one's own social and cultural reference group can be in the search for adequate forms of rehabilitation (cf. also Miles 1999). In his article, Kisanji indicates the awareness-forming potential of folk songs, proverbs and poems for school children in Tanzania, as regards both people with disabilities and the pupils' own traditions (cf. also Devlieger, see pp. 169–177). In certain cases, this *"archaelogy of knowledge"* (Foucault) brings to light thought structures related to disability which have clear advantages over those shaped by dominant world-wide biomedical Western attitudes (cf. Kasonde's contribution); these could be the way forward for both South and North.

So what is suddenly motivating those from the Centre to now do what they neglected to do for years? The feasibility and success of projects, both of which have to be documented for the benefit of funders, undoubtedly play a not insignificant role here. An interest in the *doubly unknown* (Kemler 1988) – i.e. disability and (other) cultures – may also express the wish to know more about oneself. When inhabitants of the

North start becoming receptive to the concepts and beliefs of other cultures, this is a sign that they are opening up. Part of being open to other cultures inevitably entails being open to one's own; that is, prepared to puzzle over habits and things normally seen as self-evident, inclined to inquire into their meanings, to question them, and finally, to orientate oneself anew and arrive at an altered consciousness of one's own significance (self-consciousness in Mead's sense).

DISABILITY AND *CULTURES*: SOME REMARKS ON THE CONCEPTS

How Does a Disability Come About?

If we assume that the significance of disabilities varies according to cultural context, and that what is a disability in one context is not one in another, then it would appear that the very foundations essential to intercultural understanding have caved in under our feet. Since as early as 1980, the World Health Organisation has been trying with its three-dimensional differentiation of disability to take into account the fact that it is not sufficient to perceive disability merely as a physical or mental characteristic. Instead, it has to be seen in relation to the expectations a given society has of an individual. Thus a physical/organic and mental abnormality and/or loss of function which can be demonstrably established (impairment) is only the first dimension in this model (cf. WHO 1980: 27). A second dimension – known as disability – concerns "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO 1980: 28). The third dimension, handicap, is the "disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for the individual" (ibid.: 29). This three-dimensional definition avoids a question, however, which always intrudes itself when encountering different societies: does it make sense at all to perceive impairment, if a person is socially integrated? In other words, why diagnose an impairment when there is no handicap? Or putting it differently again, the question could be posed as follows: for whom is it important to thematise impairment at all?[2] The answer could lie between two poles. On the one hand, it may be an important issue for the individual with a disability seeking rehabilitation measures that could remedy physical or mental irregularities and reduce suffering. On the other hand, impairment is thematised by those for whom abnormalities and irregularities are carriers of significance in those symbolic structures that govern their respective societies. This is not always the case in the same way. It is valid for countries of the North, like for example the U.S.A., where the only "complete unblushing male" is portrayed as a "young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight and height, and a recent record in sports" (Goffman 1963: 128). Against this background, damage of a physical, intellectual or emotional nature always carries the message of not being successful and not being capable of succeeding, of being condemned irrevocably to leading a worthless existence. And virtually any deviation carries this message of damage. Damage is also a carrier of significance in those regions where an abnormality or irregularity is seen as a message from another perceptual world, and may be interpreted either positively or negatively (see the articles by Gbodossou and Rösing).

It is surely no coincidence that the people who distance themselves the most from impairment, the individual defect, in their definition of disability, are those affected themselves. Self-help movements from different countries explicitly oppose the medical model, which concentrates on the disabled individual and aims at *undoing* an impairment as far as possible, so as to make the individual submit to a concept of normality which has no space for disabilities (see the contributions of Kern, Perez Cruz, Malinga, Miles-Paul). These movements develop their own way of seeing, in which disability becomes a variety of human needs which a society has not adjusted to and is not in a position to satisfy. The individual defect turns into the ability (or lack of it) of the society to adjust (social model). In thinking this social definition of disability through to its logical end, generally accepted value hierarchies are turned on their heads. Rehabilitation and medical care take a completely different position on the scale of importance. They are no longer placed at the beginning of social integration for people with disabilities, but become self-evident accompanying factors (see Perez Cruz: "We don't need to be cured first in order to live").

The self-help movements' social definition of disability is undeniably an umbrella, one under which people with disabilities from every possible social context can take their place without any problem. Variety thrives under this umbrella, and the fact that *those affected* are stringing together a discourse in no way detracts from the power of that discourse. Every discourse includes and excludes, legitimates and de-legitimates, operates with strategies which are often more orientated towards testing their power in the political and/or the academic arena, than towards those who are not participating in the discourse as subjects (cf. Hark 1998). Here we are faced with the second challenge that the contributions in this book have posed, in very different ways. How do experts (of any genre) acquit themselves in regard to the unique and particular life-worlds of those they study, with whom they work, with whom they live? How do they make themselves aware of their own ontological and epistemological assumptions, which also inform every communication (cf. Marfo's contribution)? These questions concern the concept of culture.

A CONCEPT OF CULTURE

Let us assume that structures of interrelated meanings are what regulate social life. These kinds of symbolic orders take shape in speech, in religious beliefs, philosophies, family structures, gender arrangements, the relationship between humankind and nature, in art and value systems, to name only a few of the elements which can be subsumed under the generic term *culture*. These elements are almost always the result of a long history of encounters, demarcations and combinations of symbolic orders. Symbolic orders are at the same time essential orientations in socialisation. To the extent that individuals stand in a relation to the surrounding order and find ways of dealing with it, finding affirmation in or else dissociating themselves from it, so they develop as conscious persons. Every culture receives a dynamic impulse from the fact that the relationship between signs and symbolic content leaves room for interpretation (take for example the word *culture* [=sign], whose symbolic content has been defined again here for the x-thousandth time) (cf. Sahlins 1994: 310ff.). When people whose socialisation has taken place according to different orders meet, this cultural dynamic becomes evident. Viewed on the level of interaction, its character (initially at least) is one of communication difficulties. On the level of the individual, an identity game results: for some it represents primarily an enrichment of their everyday life and widening of their horizon of perceptions, for others a drawing of boundaries and a struggle for power "which needs to be fought anew in every social relationship" (Hofbauer 1995, our translation). People with disabilities develop their identity with reference to a symbolic order which allocates them a special place. Devlieger argues in his contribution that this place often lies in "no man's land". With a disability, people are neither familiar nor unfamiliar, neither well nor ill, both irresponsible and responsible. This place *in-between* is not the same in all cultures; and what it means for a migrant with a disability to have to orientate her or himself in different symbolic orders is shown by Ouertani's article.

What Can a Perspective of Intercultural Comparison Offer?

While it is not possible to engage in an exhaustive discussion of the potential and limitations of intercultural communication here, the editors consider it important to mention three points which ought to be included in a discussion to which this book will hopefully bring a new impetus. Firstly, intercultural communication presupposes a large degree of self-reflection, relating both to one's own position, and to the assumptions underlying one's perceptions. In the North, the significance of the self-reflexive discourse is being increasingly recognised – a necessity resulting from the structural inequality between the participants when people from North and South communicate. Inhabitants of the South as well as migrants have been and are often forced to acquiesce to symbolic orders which negate them as equal players on various social levels. The task of developing an identity from this was and is left to them. In comparison to the experiences of coercion or force which so often accompany this search for identity, and have turned and continue to turn it into a tightrope walk, people in the North are able to develop their identities in ethnocentric, if not racist and xenophobic ways, with relatively little interference, by discriminating against what is identified as foreign (ibid.: 19). In response to excluding behaviour of this kind there seems nevertheless to be one possible sanction, i.e. not to allow communication to take place. Secondly: if we see cultures as mixtures of symbolic orders in a globalised world, coalitions may arise which run counter to national, territorial and ethnic affiliations. In this book, Kofi Marfo thematises the extent to which academics and researchers can be seen as members of different cultures at all, if their professional socialisation takes place within one and the same order, which structures their perceptions. It is by no means unthinkable that two sociologists from Mexico and Germany are able to communicate with more immediacy with one another than when the one communicates with her Zapotec relatives in the highlands, and the other with her aunt and uncle in a Westphalian village. The third point concerns the danger of seeing cultures as static, self-contained structures – a viewpoint which often also involves considering foreign traditions as something that one has no right to interfere with, and that should not be touched. What results is the opposite form of behaviour to colonialism: where earlier other traditions – and these are also cultural concepts – either didn't interest anyone or were else suppressed and forcefully assimilated, now they are voyeuristically kept at a distance, and are trotted out routinely as a reason why it is impossible to find a common meeting-point. Traditions, though, are the result of thousands of years of communication; or, in the words of Al Imfeld: "Traditions are like geological layers going back at least 300,000 years" (Imfeld 1999: 5, our translation). The dynamic of traditions often produced encounters which were not *herrschaftsfrei*, i.e., they entailed some form of domination (for example wars [cf. Tietze's contribution], slavery, colonialism, assimilation). By no means all the forms and structures established and strengthened in this process have to be treated with respect and approval, simply because they bear the label *traditional*. This applies for example in the case of barren women who are ostracised and expelled from their social environments, as Erick Gbodossou describes for the Fatick Region in Senegal and the Mono Region in Benin (in this collection). Traditions have always changed, and can always change further. Democratically oriented communication is able to play an important role in this.

What Role Can Cultural Studies Analyses Play in the Understanding of Disability?

As already mentioned, people with disabilities, in that they are people with stigmas, abnormalities, irregularities, are very often themselves carriers of significance, and "stand out". Stiker, writing in this book, thematises the issue that although "power, sexuality, religion, poverty, gender" have been and continue to be analysed in relation to their symbolic content in different cultures, infirmity (as a generic term for illness and disability) is seldom addressed. In the social sciences, the structural functionalist approach categorises people with disability as being no less *deviant* than criminals or homosexuals (an "assignment to a group" which Goffman's sociology of everday life approach fails to relativise); whereas the historical materialist disposition regards the status of people as *disabled* in relation to economic usefulness. In politics, disability is counted as a social problem; to *solve* it, acceptable solutions are being sought (acceptable above all to the state coffers, that is). But statutory measures are often ineffective. In Germany, for example, the law lays down that enterprises above a certain size have to employ a certain proportion of people with disabilities. Only too often do employers prefer to pay a monthly "fine" of DM 250, rather than take on a person with a disability. The widespread view that having a disability means *incomplete* or *defective* life may provide an explanation for this behaviour (cf. Kern in this collection). Thus, analyses from the fields of cultural anthropology and sociology of culture are able to contribute to a more complete analysis, in that they register and include the differing symbolic content of the phenomenon found in societies (cf. also Devlieger, see pp. 297–303, and Dossa in this collection).

THE CHAPTERS AND INDIVIDUAL CONTRIBUTIONS

The meeting of symbolic orders is a theme running through all the chapters and articles. *The first chapter* includes contributions which can be seen as exemplary presentations of concepts and beliefs relating to disability in different cultures. As such, they refer to various areas of symbolic orders. *Rösing* and *Holzer* examine local contexts in South and Middle America, and show how the cultural meaning of disabilities determines the way those affected are treated, as well as their daily lives. Both articles relate the ascription of meanings to the structuration of economic and social life in the respective societies and by so doing, expose their striking differences to postindustrial Western society. The contributions of *Gbodossou, Kisanji, Miles* and *Turmusani* deal with various areas of the symbolic order in local contexts. *Gbodossou* presents the holistic religious and spiritual cosmovision in two regions in Senegal and Benin respectively, in which disabilities cannot lead to exclusion from social life (with the exception of *barren* women, see above). People with disabilities frequently find their place in society as traditional healers. *Gbodossou* gives some results of a wide-ranging survey of this profession, people with disability and people caring for them in the named regions. *Kisanji* shows the symbolic power of images in dealing with disabilities, and how they occur in folk songs, proverbs and stories. He demonstrates how these could be included in a concept of integrative education, sensitising pupils to their own cultural context, and also to people with disabilities and their many-sided and also positively-seen roles. Using the example of the South East Asian context, *Miles* outlines a way of obtaining knowledge of the history of disability and forms of rehabilitation. By analysing ballads, for example, societies can gain insights into the meanings of disability and thus free themselves of the myths imposed on them from the outside. *Turmusani* analyses positive and negative attitudes to people with disabilities in Jordan, and discusses the extent to which these can be traced back to the *Qur'an*. The author also thematises the changes in meaning in relation to disability that are being initiated by the work of NGOs and which reinforce certain negative, individualising effects of the image found in the *Qur'an*.

The last two contributions in this chapter have as their focus the meeting or else the comparison of concepts from North and South. *Kasonde* contrasts bio-medical thinking with the everyday notions and knowledge of people in West Africa and indicates various social structures which underlie these concepts. *Albrecht* discusses the extent to which cultural comparisons can contribute to improvements in the practice of special education in the North. With reference to a comparative study of the role of the father in the upbringing of children with a disability, he illustrates how comparative studies of culture can contribute to a better understanding of the conditions and problems connected with one's own methods of child rearing.

Chapter II concerns three specific areas of experience related to the vast topic of migration. Against the background of her experience as a special educator, *Kalyanpur* examines four concepts used in the bio-medical approach to disability, showing how and where these collide with the cultural conceptions of migrants (disability as a physical phenomenon, disability as a chronic illness, disability as an individual phenomenon that can be fixed). On the basis of his personal experience of migration, *Ouertani* thematises differences in the systems of social security in Germany and Tunisia. From her point of view as a special educator, *Merz-Atalik* discusses how the meaning attached to disability is not so much culturally determined – if culture is related to national or territorial affiliation – as dependent on the family or even on the individual.

Chapter III deals, on various levels, with cultural encounters in development cooperation. *Devlieger* views the current state of affairs in the dialogue between North and South as characterised by a competition between global and local knowledge systems. He sketches how this competition could be overcome via cooperation between universities, the political sphere, and (self-help) organisations. *Tietze* and *DeKeersmaeker* both report from their NGO work in various Southern countries. Using the example of *Medico International's* work with landmine victims in Angola, *Tietze* describes the difficulties that arise on the one hand in the context of the "culture of poverty" (Lewis 1971) in war zones, and which on the other may be encountered in the attempt to make systematic assessments and estimations of disabilities. With reference to his experiences in a number of projects run by *Handicap International, DeKeersmaeker* discusses the relevance of cultural concepts. The following three articles address the meeting of cultures on the level of project planning. *Burck* thematises the significance and the difficulties of obtaining local knowledge about disability and integrating it into project praxis. *Wirz* examines the aspect of international training courses for project planners and managers (in particular CBR projects[3]). She emphasises how important the different preconditions with regard to expectations of training, expectations of service and expectations of service planning which the participants bring with them are for the success of the course. *Finkenflügel* analyses the daily routine of CBR projects, in which expatriate and local co-workers meet on various levels of project organisation. The last two contributions in this chapter refer to the cooperation between professionals and parents. *Kalyanpur* names three cornerstone Western values – equity, choice and individualism – which can lead to communication difficulties between special educators with a training orientated towards Western knowledge systems, and parents from Asiatic cultural milieux. *Van der Putten* presents the results of a study of child rearing practices which Jamaican mothers routinely carry out with their infants. These practices are a part of that knowledge which is handed down from mother to daughter, and has the purpose of encouraging growth and suppleness in the children. These are beneficial rehabilitation methods when an impairment is present. They also enable mothers to identify such impairments early on. The practices are an example of local knowledge that it is both useful and necessary to take into account in rehabilitation projects.

In the *IVth chapter* four authors who are active in the self-help movement present their organisations. *Kern*, U.S.A., thematises the fact that women with disabilities are particularly affected with regard to rehabilitation, CBR and development projects in both North and South. By the example of the international whirlwind networks, she demonstrates the problems that arise because the specific situation of women (with disabilities) is, again and again, not given sufficient attention in project praxis. Women have drawn their own conclusions about this, and in 1994 founded whirlwind women, a network that can now point to experiences in many countries in both North and South. *Perez Cruz*, Mexico, gives a portrait of a self-help group in Oaxaca City. He thematises the priorities of the group's work, as well as the concept of disability and of an independent, autonomous life towards which the work is oriented. *Malinga*, Zimbabwe, stresses the need for people with disabilities to fight for equal rights, and rights in general. *Miles-Paul*, Germany, states which central policy principles are embraced by the international Independent Living Movement: equality and anti-discrimination laws; the de-medicalisation of disability; no singling out or exclusion, and the greatest possible integration into the life of the community; the greatest possible control over their own organisations and over the services for the disabled by the disabled themselves; peer counselling and peer support for the empowerment of people with disabilities (cf. "Basic Principles of a Self-Determined Life" in Miles-Paul's contribution, pp. 279–280).

The Vth and final chapter deals with methodological questions which have arisen in the course of researching local concepts and beliefs about disability in different cultures. Cultural concepts are not simply revealed to strangers to a culture; a whole series of conditions and boundaries which get drawn into the research, or else are inherent to it, have to be considered as well. Ethnology and anthropology have a long tradition of developing different methodologies and methods for tracking down cultures and their development, and for reflecting at the same time on the cultural assumptions that the researchers contribute themselves. Some methodological approaches and methods are explained in the contributions to this chapter. *Groce* starts it off with some general ideas which concern both the relevance of culture in looking at disability, and the demands which should be made on the methodologies used to research the phenomenon. In this, she places great emphasis on interdisciplinary project designs that cross the borders of specific subjects and professional fields. *Devlieger* presents arguments for a "cultural theory of disability", to be developed trans-culturally while at the same time being able to grasp the specificity of particular cultures. Disability can, universalistically, be termed an "interstitial category", which "acknowledges that people with disabilities are the same and different" (see page 299). The theory becomes relativistic when cultural areas in one place at one time are studied with regard to these kinds of interstices, like for example language, art, rituals, religion, political discourses, etc. *Dossa* too sketches methodological-theoretical guidelines for the study of disability, ethnicity and gender. She stresses the significance of action-theory approaches (for example, Giddens' "structure and action" [1979]), in order not to see culture as a static construct. Those affiliated to the culture are not only products (=victims) of it but (re)produce structures themselves. By means of three areas – live narratives, space and embodiment – subjective and objective mechanisms can be identified, which produce stigmatised differences like gender, ethnicity and disability, and confirm them again and again. *Marfo* presents philosophical and methodological reflections, relevant both to researching cultural concepts, and to research itself as an "intrinsically cultural activity" (see page 317). As long as the epistemological (concerning the relation between the knower and the knowable) and ontological (relating to the the nature of reality and what is knowable) assumptions that researchers bring with them into their studies are not made explicit, their results necessarily lose something of their validity. If the assumptions are made explicit, then it becomes clear that the division into local and expatriate investigators becomes blurred, since researchers in both the South *and* the North are socialised into scientific concepts that have been developed in the North.

The next two contributions deal with the contextualisation of disability on the level of project praxis. *Vreede* takes up the assertion that concepts of disability do vary widely and are dependent on usual activities of daily living (ADL) in the community under study. The social context determines which activities it must be possible to carry out, alone or in cooperation with others, to master daily living. This concept can be seen as the basis for an empirical approach which leads to a definition of disability which "establishes the priority needs and solutions from the community's perspective" (Boyce/Weera in this collection). The potential of ADL is demonstrated by *Boyce* and *Weera* in their work in war zones. They examine the extent to which different definitions of disability are suited to planning "immediate, institutionalised and community based rehabilitation programmes which can alleviate human sufferings and the disruption of routine activities, caused by physical injuries". They favour the ADL approach (*Vreede*, see above), since concrete, ideology-free socio-environmental factors can be included in the project planning and work. *Turmusani* presents a further research method which has found acceptance not only in research *on*, but also primarily *by* people with disabilities – the so-called Participatory Rapid Appraisal Method. In this method, the aim is to involve the target group on all levels of the research planning and execution, and thus to link the research process with the process of project implementation. Stiker's contribution concludes the chapter with a discussion of cultural theories of disability. He stresses the significance of the symbolic content which disability has in every society, in one way or another. The contribution of Historical Anthropology is discussed with reference to, and in dissociation from discourses from sociology and anthropology in particular. The overview over theories and developments which results in this way creates a meta-reflection, upon the background of which different directions in view-point and thinking appearing in the reader can be considered (anew) and put into place.

Editorial Note

In this reader there are articles written in both British and American English. The respective spelling conventions have only been kept consistent within each article. By consciously preserving these differences, we hope that the reader will succeed in reflecting the multicultural nature of the symposium from which it results.

Quotations from texts which are not in English, and of which no English translation exists, have been translated by us.

NOTES

1 This happens for example when the IMF and the World Bank make structural adjustment measures a condition for awarding credit.

2 The WHO nowadays uses the terms *impairment, activities* and *participation*. But these new dimensions are still impairment-based (see Vreede in this collection).

3 CBR "is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities" (see Boyce and Weera in this collection, p. 337).

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Concepts and Beliefs about Disability in Various Local Contexts

STIGMA OR SACREDNESS. NOTES ON DEALING WITH DISABILITY IN AN ANDEAN CULTURE[1]

Ina Rösing

"One is not disabled, one is made disabled" ("Behindert ist man nicht. Behindert wird man"). This slogan appeared on a poster produced by the charity Aktion Sorgenkind and refers to Article 3, paragraph 3 of the German constitution, which states that "nobody should be discriminated against on the grounds of a disability". This poster campaign is supported by 85 other German organisations for the disabled and says simply that it is society's reaction which creates disability. Stigma, legitimisation and exchange value are three important concepts towards an understanding of the cultural differences in the construction of disability. Today stigma is understood as being visually marked in a *negative* way. With visible stigma an illness becomes *legitimate*. Legitimate illness leads to sympathy, consideration, help and to culturally appropriate behaviour toward the sick person. Illness can also have a profit, a bonus, an exchange value. And quite a number of sick or disabled people know how to use this bonus best and most constructively.[2] In the following text I will present some case studies of disability in the Andes and discuss them from the point of view of cultural resources for and barriers to coping with disability, as well as from the point of view of the concepts stigma, legitimisation and exchange value. The case reports are from the Kallawaya region in the Andes of Bolivia (the province of Bautista Saavedra), where I have been carrying out field research for the past fifteen years. Before presenting the case reports, however, I must first present briefly the living conditions in this area. For it is only against this background that cultural resources and barriers when dealing with disability can become clear.

LIVING CONDITIONS AT A HEIGHT OF ALMOST 4,000 METRES

The Quechua-speaking people in the Kallawaya region live from farming and livestock, at a height of over 4,200 metres, keeping lama and alpaca herds. The potato is the chief form of nourishment, there is an abundance of herbs, some vegetables at certain heights only, and very little meat. The villages, which with very few exceptions comprise 20 or 30 families, are situated at a height of between 3,500 and 4,200 metres. This mountain world is very rugged. Except for a few bumpy gravel roads, there are mostly only narrow mule tracks connecting the villages. One family's fields are often several small parcels of land spread over a large area so that working in the fields for one day means a long march east and the next a long march west. Pastures for the sheep and a few cattle are few and far between at this height and you have to go a long way to get to them. They are often a day's march away, so that the little shepherds (they are mostly children) have to spend the night outside. The families have many children and all the children are expected to work from the age of three, four or five – fetching water from the springs, looking for sticks, brushwood or dung for the hearth fires, taking the sheep to pasture, looking after younger brothers and sisters, helping in the fields. Everyone is needed, everyone has to lend a hand. The climate is harsh in the Apolobamba-Kordillere. There is the dry season when the temperature at night drops to minus ten degrees – or in the case of the alpaca shepherds to minus twenty degrees (although by day they can rise to 25 or 30 degrees), and the rainy season, which is much more unpleasant – then the temperatures are always just above freezing and it can literally rain for weeks on end. The huts are between 12 and 20 metres square. In a native hut there is no water, electricity or heating. The cooking is done over a clay hearth. Usually one single hut is used for cooking, eating and sleeping. Working, talking, loving, giving birth and dying – all take place here.

The religious life of the Quechua people who live there is very rich and extensive. Nominally they are all Catholics but in reality it is only their pre-Christian religion which is really alive. Their highest deity is Pachamama, Mother Earth. The mountains are the dwelling places of the gods, as are the places of offering of the huts. Wherever lightning strikes, a god takes his home. The gods are worshipped through sacrificial offerings and prayer. The relationship of the people here to the gods is governed by the same principle as that among the people themselves – that is to say according to the principles of reciprocity, of a balanced give and take. Giving and accepting help are two of the most common acts amongst the people here. And taking from the gods – well-being and health, protection and fertility of people, animals and fields – and this cannot happen without *giving* – the sacrificial offerings, the worship, the prayer. These are just some remarks on the living conditions of the Quechua people of the Kallawaya region, some of whom I would like to introduce you to in more detail later.

CASE REPORTS FROM THE ANDES

René with the Crutch

René is about 30 years old, married, with four children. He lives in Amarete. René has polio in his right leg and drags himself about on his crutch and his one healthy leg with difficulty. He is so disabled that field work, looking after animals, hut building, the long distances in the Andes and many other normal daily tasks and demands are impossible for him. All the men join in the building of the community hut. René cannot. He keeps the list of who has contributed to community work, when, and for how long. He directs the men's food and the timing of the necessary house building ritual. He looks after the guest (myself). He keeps morale high. No house may be built in the Andes without making an offering to the most important gods so that they will protect the house and everything that will take place in it in future. This *tejsi* ritual has to be carried out by a recognised ritualist. Amongst other things a number of so-called sacrificial nests are prepared – small bowls of cotton wool into which various ingredients such as carnation blossoms, crumbs of incense, coca leaves, etc. are laid. These sacrificial nests are dedicated to particular gods and represent pleas to them for protection. There are, for example, a series of sacrificial nests for the gods of lightning so that they will not strike the village's planned community hut. There are offerings for the most important mountains of the region, which are responsible for food, clement weather, rain at the right time. If there is no food, then the people in the community hut will go hungry instead of sharing ceremonial meals. The preparation of these sacrificial nests is a long and intensive, and above all *communal* process. And the sacrificial nests themselves take in symbolically all the people's wishes and all preoccupations – this is actually made visible in their forming and audible in the accompanying prayer. It is not just the medicine man or ritualist who is active with all others sitting passively by, watching and listening. No – everyone is continually active throughout. Some of the men look for good coca leaves from a bag of coca, others pluck the blossoms, and yet others break up the lama tallow into small pieces. They all bring what they have prepared to the ritualist, who is always the first to fill the sacrificial nests. Once he has filled them, the other people involved have their turn – for each of the ingredients. Thus if the ritualist, for example, has just placed a number of coca leaves in the sacrificial nests he then calls the men and each of them must place some leaves in as well, praying at the same time. The same procedure is followed with the lama tallow, the carnation blossom and so on. So the congregation does not just sit stiffly by, everyone is constantly in motion, moving towards the place where the offering is being prepared, approaching, depositing and then moving back to their place.

And what of René? This continual movement backwards and forwards would be impossible for him. Would a possible solution be for him to position himself near, or indeed right next to the medicine man? That would not work. In Amarete, the village in which René lives, everybody has their own particular, predetermined position depending upon their threefold gender. Here everyone has three genders. Their multiple symbolic gender is dependent upon the gender of their fields and the official office that they hold. Here even official offices have a gender, and their gender, together with that of the fields, determines the seating plan and movement in the room. So within the context of movement allowed him by his disability, René is strongly predestined by the symbolic gender organisation of the Andean space. And according to these ritual rules he has to sit a considerable way away from the ritualist. So how should he act if he cannot continually keep hobbling backwards and forwards? In the provision of the gods the Andean culture recognises the principle of representation. A person can have himself represented before the gods. A ritual on the top of the holy mountain Esqani may serve as an example.

I have climbed the 4,800 metre high Esqani mountain several times with great effort. When I was up there for the first time I had *said farewell* to the Indians who had accompanied me. I was utterly worn out and simply could not imagine how I was ever going to manage to get down the steep, loose slates on the edge of the precipice for hours on end, carrying 20 kg and with an injured knee. Things turned out alright, however, and I actually climbed this holy mountain several times after. Up on the dizzy height of Esqani an impressive ritual took place. The first time that I was there I was amazed by the amount of hats that the people had brought with them, pulling them out of their pockets one by one to give to the medicine man, who consecrated them over the glowing incense bowl. They were not their hats, however. Slowly I learned to understand the representation system before the gods better. They were the hats of other people who were not able to make the climb, but who nevertheless wanted to take part in the worship of the god of Esqani mountain. They were represented by a *prenda*, a pledge: the hat. When it comes to the matter of the continual ritual libation, spraying Mother Earth with pure alcohol (first, in a ritual gesture, she is given a drink and then you take a drink of the awful, burning swill yourself), and I just do not *want* to drink any alcohol – then I make my libation and pass the bottle of alcohol back to the person who gave it to me, asking him to drink to Mother Earth – in my name. This is also being represented before the gods. Behind this system of representation lie ideas of a much broader *body-concept* than we know. A piece of clothing is a part of myself. And so an act of witchcraft carried out on the clothing of the intended person can, according to the beliefs of the Andean people, cause death through a pledge representing the person. And so the Andean culture offers René a solution. He sends his *chuspa* (coca leaf bag) up to the medicine man, having it passed along from hand to hand – or somebody who is sitting next to René takes his offering to the table. From his *chuspa*, which is a part of him, the medicine man takes the good leaves and places them in a sacrificial nest and it is René's hand which puts them in.

In Amarete everyone has to go through a long hierarchy of offices. There are certain offices – those which have to do with a lot of movement through the village, with overseeing the fields and so on – which René cannot carry out. But this can be balanced out. He contributes something which is a rare commodity in the village: the ability to read and write. For very early on he realised that being able to read and write would be a very important resource. It is true that today by law every child living here must attend school – but as the children, as I have mentioned, are needed to look after the animals, to work in the fields and to collect brushwood and so on, they only attend school on a somewhat irregular basis. And after they have left school the children, who have learnt to read and write despite the irregularity of their school attendance, then simply forget it – there is just not enough call for it. René, however, was determined to attend a school for further training and today his reading and writing are excellent, and thus he is important for the village. In his village he is not regarded as inferior, not at all, only as different. And to compensate for his being different there are rules which he fulfils. The balance of his contribution to the welfare of the village – the reciprocity – is not disturbed.

Deaf and Dumb Nicasio

Nicasio is in his mid-thirties, single, and lives in his mother's hut together with his married brother and his six children. Nicasio has been deaf from birth. He has never learnt to speak. A small arsenal of inarticulate sounds comprise his whole vocabulary: yes and no, agreement and protest. But the sound of protest is very seldom heard. For Nicasio, my *ahijado* (godson) by ritual, has a really happy nature. His infectious laugh relaxes even the grimmest meetings and opens hearts (mine, too). Nicasio is strongly built and healthy. He is agile and hard working. He does the work of three in the fields. For his village he will go the furthest distances without complaint to carry messages or complete tasks. Of course he cannot hold any office. But he is a full member within the sphere of work from which everyone lives, the work in the fields and community work for the village – clearing paths after rock falls, clearing irrigation channels and so on. Only one thing worries Nicasio. He would like so much to marry. In the Andes marriages are still often planned and arranged. This is also the task of the *madrina*, the godmother of the person concerned. And Nicasio was very keen to have me as his godmother – with the aim of having me find him a wife. Just how he explained this to me – without being able either to speak himself or to listen to my words – gave rise to scenes which had us both killing ourselves laughing. But we understood each other. Why is it difficult for Nicasio to find a wife? Is this perhaps the punishment for disability? No. He can have a family and he can feed a family. It took a while before I understood why my third suggestion – I had found a girl who would have married Nicasio – was not accepted. His mother (a widow) wanted to keep Nicasio for herself (she confessed to me). He was such wonderful help around the house and home.

Magno from the Place of Evil Spirits

Magno died two years ago. He was eight years old, a sweet little boy with large eyes. I do not know the cause of his disability. But his parents naturally did. Magno was born in a place inhabited by evil spirits. In any event he could not stand on his legs, or only for a short time and with great pain. During a long period of rehabilitation in La Paz he had learnt to walk a little and above all to use crutches. But his little arms were affected, too, and each movement was exceptionally difficult. Despite this he did learn to go behind a bush by himself. Any growing child who cannot do this is a real everyday burden for the family, and is indeed disabled. But Magno could neither help in the hut nor out in the fields. He could not speak very well either and was mentally handicapped to a slight degree. But this would not have counted had he been physically fit. As it was though, the little chap was doubly disabled. I visited the family a lot, lived with them in a distant hut at a height of 4,400 metres in the dry season, where the animals – llamas and alpacas – were herded on these lonely heights for months on end to find food. When Magno was small – in other words *bearable* in the literal sense of the word, his disability posed no problems. His parents were loving, his siblings were loving. He was always given priority. He lacked nothing. But when he was no longer *bearable*, he had to stay behind in the hut when everyone else was in the fields and the pastures. Sometimes for days. Just how infinitely hard it is to be alone in the Andes can only be measured if you are familiar with the conditions there and have experienced them yourself. There is, as already mentioned, usually only one hut, perhaps 10–12 metres square. Everyone sleeps in it – parents, grandparents, children, guinea pigs, small animals and guests. There is a constant coming and going in the hut. You grow up there as a child and are never alone. And as a grown-up you are also hardly ever alone in the hut.

In my first year in the Andes a Quechua woman called Maria lived below my hut; she had no bed of her own. She always lay down to sleep at the feet of the master's bed, of the mestizos, or in the kitchen where half a dozen Indians slept. I gave her a small hut next to mine, so that she could have some space to herself and her own place to sleep. What a ridiculous idea! From that point on all the guests who had previously slept in the kitchen hut, now slept in the small hut next to my own. It was not possible for Maria to sleep alone. Being alone is a threat of the most extreme proportions. But as little Magno grew up he was often alone. When I visited the family again and asked after Magno, Isidora, my *comadre*, the mother, broke down in tears and pointed west. The graveyard where Magno now lay is to the west of the village. What happened? Nobody knows for sure. He was alone. When his father came home he discovered Magno had terrible stomach cramps. Had he eaten something bad? What happened? Nobody knows. He died a few hours later. Of course nobody had killed him. But he had been alone. He was mentally handicapped to a small degree. He was not safe. And so something happened which caused him to die, which brought about his death. This, too, is an Andean way of dealing with disability.

The Old Medicine Man Valentin Quispe

Valentin Quispe, the ancient medicine man, became nearly 100 years old. He was almost blind and towards the end could no longer move or leave his bed. Valentin Quispe is the man in the Andes, where for 15 years I have had my hut, whom I loved the most. He was also my chief teacher, a man of deep and extensive wisdom. His fate was not easy. It is not easy to see your wife and then each of your eight children die before you. The death of his last two sons affected him particularly strongly. Isidro, the eldest son, over fifty at the time, was also a medicine man and often worked with his father. He died a long, slow death. At least there was Pedro left, my *brother* (father Valentin Quispe had ritually adopted me, so Pedro was my brother). He was a strong, healthy man. One evening he did not feel very well, he had a stomach colic, and twenty hours later he died – in the arms of his old father. Father Valentin's grandchildren were already grown up and had their own families and huts. His widowed daughter-in-law had her own fields and animals to look after. There was nobody to attend to father Valentin. Until only a few days before his death father Valentin was mentally alert. But as far as everyday life in the Andes was concerned he was totally disabled. He was disabled because he got in the way of life. It just is not possible for anybody to stay with him, look after him. Just before his 100th year of life father Valentin slowly starved to death ...

Crippled Hands, Vocation and a Prayer from Ecarnación

For the ritualist of the Andes hands are especially important. Offerings are prepared with his hands, with his hands he lifts up the bowl of incense, with his hands he places the offerings in the sacrificial fire. When medicine men and ritualists refer to great ritualists of the past in prayer, they do not say: I am acting here in the spirit of Valentin Quispe, for example, but rather they say *Valentin Quispeq makinmanta* – that is, not in the spirit of Valentin Quispe, but *in his hands*. For all white rituals – healing rituals for people, collective rituals for the field, rituals for calling rain and so on, the *right* hand is especially important. Right is the hand for *white actions*, for good – the left hand is for black rituals. Which of you is the chief ritualist, I once asked my ritual relations in the neighbouring village. Mariano, of course, they immediately replied. *Waq mana kanmanchu*. It could not be anybody else. Why, I wanted to know. *Makiyoq, makiyoq payqa*, came the answer – that means literally that he is the owner of a hand, a very special hand. And his right hand is indeed special. The four fingers are not developed. He has a thumb and the other four fingers are joined together into an unformed *hand*. And it is this that gives him his vocation.

When, in this very village, I was present at a collective ritual which took place over the course of one day I was no longer surprised when I saw that the assistant ritualist Angel *also* had a crippled right hand. A pair of ritualists with a vocation if ever there were! In their actions, in the delicate movements, etc., their hand did *disable* them to a great degree, but despite this, in the Andes this is not regarded as a disability – it is a *vocation*. What is different, if devalued, is a disability. Here, however, being different does not devalue, it enhances. *Encarnación Mamani*, also one of the really great ritualists with deep and extensive knowledge, is above all a master of the hour-long, dramatic prayer to the gods (cf. Rösing/Apaza 1994). His prayers are full to the brim with allusions to something which we perhaps would term disability. Just a short excerpt: *Ankari mellizoyoq, Gloria tara zunakiyoq. Ankari chakillayoq, gloria kalulayoq, Ankari kukilluyoq, Ankari sank' ayoq, Ankari ananayoq, Gloria makillayoq* ... and Encarnación speaks this with a hammering rhythm, like a drum-roll. Two words are repeated again and again in this section of the prayer: Ankari and Gloria. Ankari is a sort of *divinity* in the Kallawaya region of the Andes – I cannot in the present context go into this important, many-faceted figure (cf. Rösing 1990a; Rösing 1992). In this prayer Ankari is used as an honorary title which is connected with a number of different invocations. In the same way Gloria – borrowed from the Catholic church – is used as an *honorary title*.

And the things that hold these titles and which are summoned by them – these are all various sorts of stigmata: crippled hands, swollen heads, liver spots, feet first births, twins. And the prayer just quoted could be translated roughly as follows: "You much honoured carriers of crippled hands, you Gloria-bearing lame, you twin births blessed by the Ankari God ...." And it really is the case that *being different* in the Andean context does not mean you are devalued, but given value, it is interpreted as a sign of vocation. This not only refers to marks on the body, but also to all anomalies to do with birth. The most significant case of *being different* to do with birth is the twin birth. Anybody in this context has a vocation – he may have a twin brother, one of his parents may be a twin, he or she may have fathered or given birth to a twin. To be within the context of a twin birth gives you a vocation because twins are created through lightning. It is the god of lightning that splits the child into two in the mother's womb. Thus lightning, twin births and vocation are all inextricably bound together (cf. Rösing 1990b).

Two Blind Brothers from Amarete

The brothers' father was blind from the age of forty on, their grandfather somewhat earlier. Marcos went blind at the age of seven. Today he is between 45 and 50 years old (in the Andes no one knows their exact age). His brother, Pedro, a little older than him, went blind four years ago. He has a large family. His wife Angelica is very hard working. She has given birth to twelve children, six of whom are still alive – including one son. About two years ago, two small sons, four and six years of age, died within three days of each other when an epidemic swept through Amarete leaving hardly any family untouched. How do Marcos and Pedro cope with their blindness? (Their blindness is total, they cannot even tell the difference between day and night.)

Marcos lives in a hut on a collective courtyard which several families share – a usual occurrence in Amarete. He moves freely through the hut, court, village and fields. Marcos has visited me at least ten times in my hut. Our villages are a good five hour's steady walk from each other. Marcos does have a child to accompany him on these long walks (always one of his now blind brother Pedro's children) – but no distance seems to be too far for him. In Amarete Marcos is a respected and much sought-after man. He is a medicine man, a specialist for grey rituals. Grey rituals are for purification and casting off spells. Marcos is fetched when one of these rituals is needed. Marcos is also specialised in a black healing. Black healings are rituals for depriving enemies or opponents of their power. The black ritual that he carries out is unique in the whole region.

In the Kallawaya region there are white, grey and black healing rituals.[3] The white healing rituals are healings *for* something: for health, wealth, protection etc. The grey rituals are healings *away* from something – away from mourning, contamination, witch's power. The black rituals are healings *against* something – loss of power, damage. The black healings are kept strictly secret. And so in the whole region there are no collective black rituals – that would be too public. There are extremely complicated and beautiful collective white rituals which last three days and nights, there are collective grey rituals – but no black ones. With one exception – the black ritual in which Marcos specialises. It has to do with football! The village of Amarete is divided in four. Each quarter has its own football team. The people of Amarete are passionate about their football. They play against each other during the year. And in order that no other opposing football team can beat that of the quarter of Amarete to which Marcos belongs, he carries out a collective black ritual for his team aimed at weakening their opponents. Naturally the other teams do the same. So Marcos plays an important role for his quarter. And whether there are family healings or these collective healings, the people of Amarete are all totally convinced that Marcos can see *inside* things in a particularly lucid and powerful way in which people with sight cannot. His faculty of perception reaches trans-personal dimensions – as we might say.

For Pedro, Marcos's elder brother who went blind a few years ago, the world is entirely different. Pedro does not dare to leave the hut except to go to the pig sty, the toilet in Amarete, and then only by feeling his way along the wall of the hut. He never goes through the village. All his children have experience in leading the blind – there is not one of them that has not at some time accompanied their Uncle Marcos on one of his long walks. But Pedro will not let himself be led by his children. He does not go out. He is completely resigned, impassive, depressive and unhappy, he complains that he is useless (as indeed he is in this condition) and that everything is a burden. He is ungrateful and joyless. At this late age he has not (yet) been able to make the transition from his seeing life to his blind life.

CULTURAL RESOURCES AND BARRIERS

Having dealt with the case reports,[4] I would like to round off by suggesting a cautious interpretation under the following headings: (1) stigma and sacredness, (2) reciprocity and representation, (3) signs and disability, (4) disability and the disabled, and lastly (5) objective, subjective, social disability. I will then summarise the analysis under a series of hypotheses and end with some remarks on modernity and anti-modernity.

Stigma and Sacredness

The first observable phenomenon towards an understanding of the idea of disability in the Andes is the proximity of physical or mental stigmata – in the original sense – to sacredness. This is possibly the largest difference we can identify in the treatment of health, illness, disability, healing in the comparison between Western culture and that of the Andes. In Western culture there is no association between any forms of physical characteristics – not to mention any possible disabling characteristics – on the one hand, and any hint of culturally characterised trans-personal concept on the other. In the Andes this is completely different, as is shown by the example of the crippled hands of the *watapurichiq* (chief ritualist) Mariano and the crippled hand of his assistant Angel. These characteristics are not *disability*, but a sign of *vocation*, they must be seen in a religious context – they are the voice of the gods. And blind Marcos, to whom a very special type of trans-personal vision is ascribed, is also an example of this association: that which *disabled* him, allows him to see the unseen.

That this association between disabling characteristic and vocation exists at all means that a large number of people with greater or lesser physical abnormalities, which are by no means disabling, also profit from this. This is made very plain in Encarnacíon Mamani's prayer where six fingers, a bump on the head, a liver spot, etc. are signs of vocation, just as other *anomalies* such as being born feet first and twins. *Being different* is first of all not negative, but *holy*. This view is a cultural resource that in Western culture is not available to anybody who is marked by being different – or disabled. That this association between difference/disability and sacredness is by no means automatic is made clear by the case of Pedro. Before this cultural resource can be exploited to the full, a number of further personal and social, internal and external resources are needed – even in the Andes. But for many partially disabling characteristics – and I would like to state this as my first hypothesis – there is initially a culturally defined, positively evaluated area of meaning which can be seen as a cultural resource.

Reciprocity and Representation

The value of reciprocity, which governs the relationship of Andean people to the gods, and also the relationships amongst the people themselves, can be seen both as a cultural resource when dealing with illness or disability, and as a cultural barrier. First of all the principle of reciprocity signifies a high level of compensatory ability. If you cultivate my field – René, the young man with the crutch might say – then I will write a letter to your daughter in Cochabamba for you – or take over your task as secretary at the village meeting. If you climb up the building and carry up stones, then I will organise the food and keep a record of the division of work. This principle of reciprocity provides a form, a pattern, an outline into which the *disabled* person can fit. Nicasio, the deaf mute, cannot hold any office in the village administration – which usually every adult man in the village must do several times during his life. Why, despite this, is Nicasio not regarded as only half a person? He compensates for his release from duty by working three times as hard in the fields and at all other work in the village. For non-reciprocity, however, the Andean culture provides no comfortable waiting room. Little Magno receives – and he can give nothing in return. Valentin Quispe, ancient, blind, almost lame and weak to the point of death, can also only receive and not give. For them there is no Andean model for overcoming their affliction. For those who cannot give, the value placed upon reciprocity becomes a barrier.

The principle of representation which says that a person can be fully represented by something that belongs to him, particularly something made of cloth, ensures access to an extremely important Andean cultural resource: the access of even the most ill and disabled person to all forms of religious healing rituals – even the healing ritual on the top of a 4,800 metre high mountain. From the point of view of the effectivity factors of symbolic healing it is another matter entirely whether I use all my strength to climb one of the holy mountains where I then listen to prayers for hours on end and am blessed with incense dozens of times, or whether I simply send up a piece of my clothing. But from the point of view of Andean belief it makes no difference at all. And belief heals – through hope, through soothing. If we compare it with the Western culture, then the principle of compensation as a resource for illness and disability naturally does not seem strange to Western people. It is an excellent resource. This resource, however, has no fixed exchange value – and that is the difference to the Andes. Anybody who is physically disabled, if gifted, may just present himself as more brilliant. But intellectual brilliance alone will not entitle him to an exchange for physical help. He will have to attain that some other way.

Signs and Disability

We can learn from these case examples of physical disability in the Andes that *objectively* quite disabling characteristics or signs are assessed by different cultures in completely different ways. A crippled hand is *noticed* – becomes a sign (Mariano and Angel, the two ritualists), but it is not a sign of disability. In the Andes this sign is translated into a completely different language, not that of illness, impairment and disability, but the language of vocation.

Disability and the Disabled

In the Andes, or so it seems to me, the transition of disability into disabled also takes a different course. René has a disability. But in his village he is certainly not seen as disabled. He takes full part in the life of the village. Nicasio, the deaf mute, has a disability – but he is also a full member of his community. In the Andes, wherever the whole economic basis, wherever the life-preserving and life-supporting work and duties of the collectivity are not affected, there – despite having a conspicuous feature of an objectively disabling difference – you remain not disabled. It is as if the generalisation of *having* to *being*, the generalisation of one feature (he *does* have a disability) for the whole person (he *is* disabled) is not made as easily in the Andes.

Objective, Subjective, Social Disability

All those persons mentioned here have an objectively measurable disability. They also all feel themselves subjectively disabled – each one of them – even the medicine men Mariano and Angel with their crippled hands. *Caramba, molestawan arí* – Angel cursed once: damn, this really disables me (he meant his hand). So in the objective and subjective definition we find no real cultural differences. The difference lies wholly in the social context – exactly as the slogan on the poster said: "one is not disabled, one is made disabled".

This social attribution of disability differs considerably from the Western one – as has been shown. I will summarise a few of the main differences in the form of hypotheses as detailed below:

1. In the Andes having more disablement often means being less disabled. The reasons are, amongst others, the broader space allowed for compensation within the framework of the norms of reciprocity and representation, as well as the sacred legitimisation resource.
2. In the Andes disability can lead to two attributions (disability and vocation). In Western culture there is only one. In other words, in the Andes there is a culturally positive legitimisation of disability – doubtlessly a great social resource for those affected. This is missing in Western culture.
3. In the Andes disabled persons who cannot permanently contribute to the subsistence of the group are given up. They are allowed to die through failure to help and loneliness.
4. In the Andes – as here in the West – personal resources, be they the result of personal biography or constitution, play a major role in the social attribution of disability. Pedro, who is blind, is disabled, Marcos, likewise blind, is not. Perhaps one could even say that the intra-personal resources in the Andes play a far greater role in determining the extent of an attributed disability than in Western culture because the actuality of the intra-personal resources on the basis of the reciprocity value and mutual help, together with the non-personal resources (possessions, and so on), as well as the trans-personal resources – religion and ritual – are more equally distributed, or rather more equally accessible in the Andes than in Western culture.
5. In contrast to Western culture, where each individual must search for a sense to illness and disability, the Andean culture – as a cultural resource – always and absolutely places sense at the individuals's disposal. The causes of disaster can in principle be explained: debts to do with sacrificial offerings (even if incurred in a past generation), loss of the soul (which can happen suddenly to you anywhere), black actua-

> tions of others (witchcraft), evil spirits ... With the ability to explain the causes of each and every illness and disability, in principle the possibility to act is given: debts incurred for sacrificial offerings can be settled, souls called back, evil spirits pacified or white powers invoked as counterbalance, you can have yourself purified and released from evil spells in grey rituals. In the Andes these resources – *keeping up the ability to act* and *sense* – are not resources which must be gained individually, they are a given cultural offer.

CLOSING REMARKS: MODERNITY AND ANTI-MODERNITY

According to Cloerkes and Neubert (1987) there are two distinctive positions on the theme of culture and disability: the modernity hypothesis and the anti-civilisation hypothesis. The modernity hypothesis works from the premise that with ongoing social and economic development due to the ever more comprehensive range of medical and other provisions, there is also an ongoing improvement in the situation of the sick and disabled. At the same time traditional ways of dealing with sickness and disability and the living conditions of traditional culture are regarded almost as obstacles or barriers. Modernity is seen as a resource. Most development aid takes place under these colours. The opposite thesis states that modernity makes the position of the sick and the disabled worse, and considers another aspect of this same economic and technical development: not the range of healing technologies provided, but the value or lack of value which makes these possible in the first place. And these are: maximisation of individual profit, egoism, the emphasis on achievement, activity and the ability to function. In traditional societies, on the other hand, where people are not concerned with maximising individual profit but rather with the collective wellbeing of the community and reciprocity, the sick and the disabled are in better hands. I think that if we place health, illness and healing within the broader context of resources and barriers, then we can overcome the simplistic views of these diametrically opposed positions and can ask ourselves with a greater degree of accuracy and discrimination where it is exactly that the cultural and social resources and barriers lie. It is to this view that I intended to contribute some material with the present chapter.

NOTES

1 A word of thanks. My Andean research in the Quechua-speaking Kallawaya region with comparative research in the Aymara-speaking region of the Altiplano, in Quechua-speaking South Peru, as well as in the Tibetan cultural area of the Himalayas is supported by the German Research Foundation, the Volkswagen Foundation, the Robert Bosch Foundation and by funding provided by the research award of the Federal State of Baden-Württemberg, which I received in 1993. I would like here to express my deep thanks for this research support. I would also like to thank all those people who have helped me to understand their culture better, and in the context of this particular paper: Marcos and Pedro Kuno, René Vega, Nicasio Quispe, Encarnación Mamani, Mariano Mamani, Angel Tejerina and the two who died – little Magno Paye and my father Valentin Quispe. And thanks, too, to my assistants at the University of Ulm, Silvia Gray and Christiane Wahl and to Dr. William Robert Adamson, University of Ulm, for his excellent English translation of this chapter. Last but not least, thanks to Prof. Dr. Reinhardt Rüdel who taught me more about disability and successful coping with disability than anybody else in the world.

2 The whole drama of a de-legitimised illness – an illness which, if you like, is denied the status of a real illness – can be studied by looking at modern CFS, the Chronic Fatigue Syndrome. No matter how ill those afflicted may feel, society regards this illness as laziness, sluggishness, sentimentality, hypochondria, as a *psycho thing*, cf. Ware's impressive study (1992).

3 Cf. Rösing (1987/92; 1988/95; 1990/93; 1991).

4 Perhaps I might insert one case history in which the disabled person is not a native of the Andes, but a man in a wheelchair from Germany, Reinhardt Rüdel, who had the incredible courage to accompany me to that inhospitable region where there is not even one single square metre of asphalt to wheel on. This person in a wheelchair is, however, totally independant, he can jump up and down flat steps, can ride the escalator, flies all over the world, can load his wheelchair into the car and so on. He can in fact do anything that a non-disabled person can – except stand and walk. How would the Indians in the Andes treat him and his vehicle, the wheelchair?

The wheelchair was initially an object which excited great curiosity. As soon as the principle had been understood, however, and the person's skill had been sufficiently observed, and once it had been established that this man could enter and leave a hut by himself without needing to have anybody continually with him, from this moment on he was accepted as a normal guest of the village (at least as far as the question of movement was concerned).

That despite this it is not easy to use a wheelchair at a height of 4,000 metres in totally impassable country without considerable help is obvious. But the particularly interesting thing about this story, and one which tells us a lot about how the disabled are treated in the Andes, is the complete and easy availability of every possible kind of help (cf. Rösing/ Rüdel 1997, a book which is a very concrete depiction of the way disablement is dealt with in the Andes).

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EVERYONE HAS SOMETHING TO GIVE. LIVING WITH DISABILITY IN JUCHITÁN, OAXACA, MEXICO

Brigitte Holzer

The following reflections arose in the course of my research in the context of the German Research Foundation (DFG) project, *The women traders in Juchitán*. My interest in the topic of *disability* developed somewhat coincidentally. The sociological-ethnological research project was concerned with the matriarchal structures of parts of the Juchitán population of 80,000 on the Isthmus of Tehuantepec, maintained by the Zapotec lifestyles of the peasants and women traders. Accordingly, it was the specific normality of these parts of the population that I was looking at, and not the various forms of *deviations* in that society. At the same time, I could not avoid being aware of handicapped people, since they participated with all the others in everyday life completely as a matter of course. 25-year-old Paco, who would be regarded as mentally handicapped in Germany, goes around town on a tricycle with a trailer and sells cheese. Lupita, who is also “mentally handicapped”, sells tortillas (maize pancakes) for her mother in the neighbourhood after school. The homeless woman who comes from Chiapas from time to time, stays around the cooks at the market and *has her fits* now and then, i.e. curses everyone loudly, is employed by the cooks to wash dishes and clothes, receiving meals and money in return. A woman who cannot walk sits at a window looking onto the street and embroiders high-quality blouses of the kind worn there on festive days. Carmen and Monica, both also “mentally handicapped”, go round the neighbourhood when they come home from school like the other women of Juchitán, who have finished their work at the market by the early afternoon, sit with groups of people relaxing in hammocks and butacas (low chairs with reclining backs), listen to the conversations, observe, say something themselves now and again, keep an eye on the small children and occupy them.

SOME METHODOLOGICAL REFLECTIONS ON THE RESEARCH INTO CONCEPTS OF DISABILITY IN JUCHITÁN, MEXICO

After the conclusion of my research on the mother-centred social structure of Juchitán, I began to analyse my observations on the absolutely natural way of dealing with disability there in the light of my knowledge of the social structures. In so doing, an interesting dynamic emerged for me with regard to the question of what I was in fact researching in Juchitán, against which personal and foreign backgrounds. How is it possible for me to investigate disability in a society whose own language (Zapotec) simply does not include this generalised category at all? Although individual defects in physical and mental functions are named (deaf, dumb, limping, to a certain extent *idiot*, see below), *disabled person* does not exist. And why am I interested in how disability is addressed *there*? The motive can hardly come from that part of the population on which my research centres, since they do not know the problem of disability in the way I perceive the phenomenon. Thus it must arise from experiences in a social and cultural environment which *does* distinguish between the disabled and non-disabled in word and deed. What, then, am I investigating in Juchitán? The phenomenon which *our* society terms disability. Why? In order to make it a significant concept (in the sense of George Herbert Mead's significant symbol) in Juchitán too? This is of course not my motive; so my motive can only be to use the absence of the distinction in Juchitán as a basis for reflection on the definitions, differences and delimitations known *here*.

This self-reflexivity on the basis of a cultural comparison is what I would like to call the methodology of my procedure. It is through the analysis and knowledge of another culture that one is able to explore one's own reality with fresh eyes. Involvement in and openness to the other culture, together with the willingness to question one's own, are the necessary preconditions. Both make it somewhat difficult to establish a consensus about such a methodology; the impression arises of wanting to represent the non-Western culture as *good* or *better*, the Western as bad or worse, which would merely be the reverse of one and the same *modernisation theory perspective* – which regards the developed world as the better, and the less developed as the worse. Claude Lévi-Strauss aptly called attention to this dilemma, and formulated this solution:

> Other societies are perhaps no better than our own; even if we are inclined to believe they are, we have no method at our disposal for proving it. However, by getting to know them better, we are enabled

> to detach ourselves from our society. Not that our own society is peculiarly or absolutely bad. But it is the only one from which we have a duty to free ourselves: we are, by definition, free in relation to the others. We thus put ourselves in a position to embark on the second stage, which consists in using all societies – without adopting features from any one of them – to elucidate principles of social life that we can apply in reforming our own customs and not those of foreign societies: through the operation of a prerogative which is the reverse of the one just mentioned, the society we belong to is the only society we are in a position to transform without any risk of destroying it, since the changes, being introduced by us, are coming from within the society itself. (Levi-Strauss 1973: 393)

It is in this heuristic spirit that, with reference to Juchitán, I propose in the following to use sociological instruments to make visible the structures of a society in which a distinction between the disabled and the non-disabled – comparable to that made in our society – is not known. Conversely, the insights obtained make it possible to consider the distinction *we* make (including the definition of disability) in a new light. A methodological procedure of this kind means seeing disability not only as a physical, emotional or mental characteristic of a person, but also as a socially produced state. We need merely to consider the history of the definition of disability in Germany to establish that the concept is not only a very recent one, but also that it varies. Statistical surveys lay down differing criteria to distinguish between disabled and non-disabled, depending on which labour market policy motivated them (see Bintig 1980). Those concerned with the education of the disabled are continuously re-defining disability. One criterion alone runs through all definitions, namely disability as the impaired ability to take part in economic and social life. Meaning patterns belonging to Western industrialised society are both manifestly and latently apparent in the definitions: anyone can take part if they are able to do so independently and without the support of others, if they are fit for work and able to withstand the competition and pressure to achieve (cf. in this regard the critical analyses of Iben 1983; Deppe-Wolfinger 1983; Stroot 1998). In Juchitán however, we find a different concept of independence, work and economy; and thus it is not surprising that the people there do not make the same distinction.

PEOPLE WITH DISABILITIES HAVE A PLACE IN JUCHITÁN SOCIETY

If people are able to work in Juchitán, they are supervised, if necessary, by members of the family and neighbours. At the same time, people in Juchitán need not necessarily work with the sole aim of making money, in order to be valued by family and society. There is a broad spectrum of activities that earn recognition and are not considered less important than work at the market. Activities such as giving each other time and attention, massaging one another, mutual visits, taking part in festivities, helping neighbours prepare for festivities, or simply sitting with others and exchanging views. In Juchitán, every single person is able to give something – or as we would say, to achieve or perform – just as they are, no matter what their peculiarities or special characteristics: like the alcoholic or people who can't work at the market "because their hand is too heavy, when they have to serve a customer" (Otilia). If they are bedridden, they are cared for at home. Things become tight when families cannot afford to free members to do the caring, or if they are not integrated into a social network. Cases of this kind, in which disabled people are neglected, do exist in Juchitán. However, it can be assumed that the number of such cases is far below the national average, since it has been shown that people's existence is far better assured than in other parts of Mexico (Oswald 1997). The flourishing regional economy (cf. Bennholdt-Thomsen 1994) safeguards the independent culture of dealing with disability.

Going by the daily rhythms of the women traders of Juchitán, it is not surprising that people who need support are supervised and cared for in the family. The economy is based very fundamentally on the production of immediate necessities. What women produce in the household and men's agricultural and craft products are sold by the women at the market. With these kinds of home industries, with work in the field, in the home and at the market, it is quite possible for children, the old or a person with a disability to be given tasks suited to their abilities and thus for them to be included in everyday work. In addition, living arrangements are relatively open, so that work in and around the house is visible, and spontaneous help with housework or caring is possible. Nevertheless, if we describe the part that disabled people play in social life in Juchitán purely on this level, it means we are failing to grasp what specifically characterises Juchitán normality and we are still thinking in terms of criteria applied here, in Germany. People participate and are not seen as a problem as long as they contribute or their care can be relatively easily organised; but such a description would not do justice to the

Juchitán yardstick, in terms of which people's participation is not in question at all. In Germany we speak of *integrating* disabled people, and in so doing, make it clear that they do not automatically belong to normality. Even if they are integrated, this does not disguise the fact that that integration presupposes segregation, non-integration, dis-integration. What makes daily life in Juchitán so fascinating for inhabitants of the Western world is precisely the *normality* of the *otherness*, the complete naturalness with which people adjust to the particularity of another person without reducing her or him to this feature or putting her or him in a pigeonhole.

IN JUCHITÁN'S SUBSISTENCE-BASED ECONOMY, EVERYONE IS *NEEDY* …

In the research project mentioned above, we had been analysing Juchitán as a subsistence-oriented society. This subsistence orientation manifested itself in the fact that production and trade did not function according to the rules of the free market. The aim of activities on the land, in the workshop or at the market is not to generate surpluses in order to reinvest, and thus increase income. Instead, the aim is to provide for daily needs. If the women traders do have surpluses, these are shared out in the form of feasts. Holding a feast means putting oneself in the debt of the people who come to the feast, help with the preparations and contribute a sum of money. They in turn will also hold feasts in order to claim what is due to them. This principle of reciprocity permeates the whole of people's daily lives with one another, creating mutual obligation and preventing thoughtless over-privileging in competition. It stops people from going it alone, both in the way they live their lives, and in upward mobility. On the contrary, the Juchitecos continuously renew and confirm their mutual dependence. Juchitán differs in this from the other prestige economies found in ethnological analyses, economies in which existing wealth, for example in the form of copper plates, weapons or carvings are wasted and destroyed in order to challenge *equals* (cf. Mauss 1990: 85f.). Instead, the Juchitecos enjoy music and dancing, eating and drinking to excess. Immediate human needs are at the centre of the festivities; for the satisfaction of these needs, networks of dependence based on reciprocity are formed.[1] My thesis is that the Juchitecos' way of accepting disability as a part of everyday life in fact expresses a subsistence orientation, not only because it places the immediate satisfaction of human needs at the centre of social activity, but also because it acknowledges the place of need, and needs, and, not least, of dependence on one another. Not only is food a means of communication at feasts and at the market, but mutual dependence is also ritualised. The need for help and support are not branded irritating irregularities in the smooth performance of daily work; instead, such needs are seen as normal, and can be compensated for.

During my stay in Juchitán I observed several times how friends were nursed and cared for at home after an operation. In every case, female relatives doubled the time of convalescence for which the doctor had ordered the women not to work or exert themselves. The convalescents were relieved of all activities, and helped to shower and dress. On the other hand, they evidently found it no problem to accept the extensive help given. In my nearly two-year stay there, it was a difficult process for me to gradually understand that the people of Juchitán see themselves far less as self-reliant, autonomous and independent, or try to be thus, than as needing help and support. The Juchitecos do not have the idea of *being able to make their way alone* – not even in the literal sense. In fact, people continuously accompany one another (Holzer 1996: 8f.). People who need help and support are thus simply not noticeable; something which is echoed in the kinds of institutions found in this city. Although in addition to an orphanage there has been a *special needs* school complex catering for children and young people with various disabilities there since 1986, there are no old people's homes, nursing homes or homes for the disabled.

... So There Is No Division between *Able-Bodied* and *Disabled* There

Dividing people into ones who live their lives autonomously and independently and ones who aren't able to or else need support makes little sense in Juchitán. The Zapotec language contains no expression which could classify disabled people as *the disabled*; instead it has only a few specific terms for various forms of disability. There are expressions for people who lack hearing, who can't speak, who can't see and who limp. Physical functions which are defective are described, but at the same time differentiated from functions which are not defective. Thus the blind cannot see, but they can speak, walk, and so on. Apart from this, the language has an expression for those regarded as *idiots* (gichaa). *Gichaa* has discriminatory connotations. The word does not refer so much to a permanent state as to a mood and is directed against another person in a specific situation. "People who are not handicapped are called *Gichaa* when they anger others or their behaviour is impossible," a cook at the market explained to me. Asunción Regalado, the mother of two pupils attending the special school, gives a reason why she finds the term particularly annoying. She tells several stories in which angry acquaintances or neighbours call her daughters *gichaa* in order to hurt her and her family. She feels very upset about this type of animosity and malice, since she is highly regarded by all. At the same time, another element of the same reality is nevertheless that the young women are not (and cannot) be specifically referred to, they cannot be told apart in other ways. They are Carmen and Monica, the daughters, granddaughters, nieces of … . Other people cannot refer to their *disability* in the Zapotec language.

On a Zapotec leaflet inviting people to Open Day at the special school, those in charge refer to the pupils as *gichaa*. "I drew the social worker's attention to the fact that she ought not to use this word. However, to this day I haven't managed to subdivide the word more finely in Zapotec, and to find different words for slighter and more severe disabilities," said Ms. Regalado with regret. Here she was also addressing a central dilemma which has strongly influenced both her and her daughters' biography, particularly in connection with the creation of the special school. When Ms. Regalado's daughters were five and six years old respectively, they spoke very badly. For this reason, Ms. Regalado wanted to have them examined in the state capital; she was opposed by her husband and all the rest of the family. "The children are healthy, they are just late speakers, they are not ill, that's the way they are, why do you want to drag them all the way to Oaxaca?!" were the "arguments" against seeking a diagnosis. For the (extended) family, the girls are *normal*, and thus do not need any specialised help or education. However, once disability actually becomes a concern, it starts to seem important to differentiate between types and grades of disability. This became a concern when the question of having the children educated and (differently) helped and trained in the special school established for this specific purpose arose.

In Western industrialised society, the differentiation between types and grades of disability goes hand in hand with laws which promise equal rights and state support for all. Ever minuter definitions, criteria and units of measurement for grades of disabilities consolidate their status as such. The range of people who are supposed to be disabled expands and the paradox identified by Stiker is established, "that they (i.e. disabled people, B.H.) are designated so as to disappear, they are named so as to go unmentioned" (Stiker 1982 in Ingstad/Whyte 1995: 8). With the category disabled, *Others* are created. All attention is drawn to the imperfection, and all abilities and individuality disappear behind it; and greater differentiation does nothing whatsoever to alter this.

In Juchitán, People Are Not Reduced to Their Disability …

Most methods we use to supposedly bring disablement closer to *being normal* – e.g. earning your own money, schooling and special assistance programmes – have nothing whatsoever to do with the normality of disablement in Juchitán. Erving Goffman's concept of *stigmatisation* helps somewhat in trying to describe how being normal is expressed there. He describes stigmatisation as the process whereby our society transforms otherness into an outsider status. Here he is referring to the process in the social interaction in which the disabled *alter* is reduced to her or his disability and the range of mutual interactions which would otherwise be possible is ignored. The person reminded of her stigma in this way knows that she is conspicuous, and also knows that her *alter* knows that she knows. This is not a word game, but instead describes a situation which is tense and not *normal*. The *perfect* person can avoid this situation, which is a source of continual uncertainty and insecurity. For the disabled person there are hardly any other situations; she is reminded of her disability again and again (Goffman 1994).

What was observed in Juchitán was different, as a little episode from everyday life will illustrate. Carmen (22) and Monica (21) both want to look for dresses for their birthdays at the market. Both go from stand to stand with me; the young women make selections, try on dresses and bargain. "What does this dress cost?" The trader names the price. "Why does it cost so much today, last week it was cheaper, wasn't it?" This the trader denies. The price, she claims, has always been the same. "Why do you ask such a high price?" The trader names the price which she regards as the bottom line. Carmen leads the shopping trip as a Juchitec trader, not as a pupil of the special school. Everyday normality in Juchitán impresses the observer from a society where she very seldom experiences an interchange like this. The saleswomen do not react to the difficulties the pair have in expressing themselves. Those interactions which are possible simply take place. The shoppers neither have to react to (possible) insecurity on the part of the saleswomen, nor do they seem to think it possible that they themselves could cause insecurity.

… Rather, They Have Something to Give Themselves

To be reduced to their disability would mean exclusion from mutual give-and-take, and that has grave consequences for the happiness and dignity of people.This was pointed out to me by Alicja Schmidt, a friend with Down's Syndrome. She and her husband accompanied me to Juchitán in 1995. Both are members of the association *Disabled helping the disabled* (Behinderte helfen Behinderten e.V.) in Bielefeld. In an interview which I conducted with Ms. Schmidt after this journey, she contrasted her experiences in Juchitán again and again with what she experienced at her workplace in Bielefeld at the workshop for the disabled.

> I never … felt I was being treated as a disabled person. Here [at her workshop, B.H.] you are really treated as a disabled person. You notice it when you talk to people. …, it's clear from the conversation if it's sincere or not. As if people just say things without meaning them, and I never felt that with the people in Mexico. It's as if the people here don't really take you seriously.

When asked, “So you didn't have the feeling that the people in Juchitán treated you and Wolfgang [her husband, B.H.] as disabled people?” she replied:

> No, I didn't have that feeling. From anyone. It made me so sad, how Chion [Ms. Regalado, B.H.] suddenly came and cried. That saddened me very much. I thought to myself, I'm sure she has a very hard time … .

Here Ms. Schmidt is referring to a situation when Ms. Regalado, feeling disillusioned and desperate about her husband's behaviour, came into our hostess's yard and let her (i.e. Ms. Schmidt, and not the other women present, although she knew them better) embrace and comfort her. She mentioned this situation with reference to the question whether she felt she was treated as a disabled person, which she denied. It appears that Ms. Regalado removed Ms. Schmidt's status as disabled by treating her as a person who had something to give her, who could help to comfort her. This is evidently not at all a normal daily experience for Ms. Schmidt. Indeed, she criticised the situation in her workshop in the light of what she experienced in Juchitán:

> I don't like to say disabled, because it hurts inside. But the supervisers have already really determined you, laid down that you have to think and feel a certain way. Lately, since we've been back here, … where I

> work I've noticed that no-one is really interested in the others, and when you have a question to one of the supervisers or something, then they say, Shut up, get on with your work. ... What are you after, do you think you're something special just because you've got married, you're called Schmidt now, and you've dared to go out of the home? But you won't get work anywhere else, you're still dependent on us.

IN GERMANY, EVERYDAY LIFE IN INSTITUTIONS IS CHARACTERISED BY THE INSURMOUNTABLE DIVISION BETWEEN THOSE WHO GIVE HELP AND THOSE WHO NEED HELP.

I admit I also have great trouble imagining Ms. Schmidt comforting one of the supervisers in the workshop. Indeed, the distinguishing feature of institutions for disabled people seems to be the unbridgeable gap between those who need help and those who provide it. Since they are defined as dependent, people living in institutions are reduced to taking. Their opposite numbers are independent, self-reliant people who are in the position to help those in need of it. In this encounter, the role of those who work with and care for the disabled, like social pedagogues and social workers, is to give the impression of *not* needing any help themselves. Therefore those who *need* help can't *give* anything to their helpers. This pattern of excluding people from reciprocity because they have been made into *takers* who can't *give* anything, is incidentally to be found time and again in the way people from the so-called *first world* behave towards those from the so-called *third world* (cf. Pixa-Kettner 1988). Widespread attitudes, prescribed state development aid as well as the more seriously-meant aid from NGOs, all formulate the wish to help, and in so doing, only too often merely reproduce the reverse side of the exploitation coin, i.e taking without giving, by giving and not taking. In neither of the cases are the two sides equal. The pattern is so striking, that it would be useful in the further analysis and cultural comparison to concentrate not on those who (appear to) need help, but on the need to *create* those who require help, a need which is so very clearly apparent in the institutions in this society.

A Comparison between Juchitán's Mother-Centred, Subsistence-Orientated Society and Germany's Patriarchal Money- and Commodity-Based Economy

Suppose we compare German society with Juchitán society as *symbolic orders*, as Luisa Muraro has termed them. With the concept of symbolic order, Luisa Muraro is referring to meaning structures which come into being through people recognising and naming – selecting – the diversity of the reality within their social context according to specific patterns of meaning relations (Muraro 1993). Women's Studies in the industrialised countries has, from the beginning, described the *symbolic order* of these countries as *patriarchal*. For example: in them, *work* is accorded great significance but what is perceived as *work* are primarily activities which are either remunerated and/or formally organised, or else those connected with the money and commodity economy. In consequence, many activities are neither seen as work nor properly acknowledged, despite fulfilling basic human needs; for instance the unpaid housework of women (or the area of relationship-creating and -maintaining work). This *mother's work* is subsistence production, in that its immediate aim is the preservation and creation of life, and not the acquisition of money and the production of commodities. Within the patriarchal symbolic order however, it is not *mother's work* that is endowed with life-preserving significance in everyday and scientific/academic thought, but that very work in the money- and commodity-based economy which is removing us ever more perceptibly from what is essential to life (Holzer 1997).

What this pattern of significance expresses, according to Luisa Muraro, is that the "origin in the mother" is not accorded any meaning in the patriarchal symbolic order. In the patriarchal system, the (significance of the) origin in the mother is deliberately ignored. On this basis the potency and achievements of women (i.e. their nurturing, providing and caring activities, and the people resulting from these) are on the one hand neither seen, named nor adequately represented. On the other, people cannot perceive themselves as dependent beings, beings with needs who rely on others, if the *mother's work* kind of subsistence production is not regarded as significant. The figure of the mother complements that of the needful, dependent and helpless creature (child, baby). These interrelations will start to become clear when we consider that section of Juchitán's population which is made up of farmers and female traders. With reference to this section, one can speak of a symbolic order of the mother, since the social, economic and cultural organisation of Juchitán is structured around a female genealogy. This concept, which refers to the female line of succession (e.g. the mother's name and not the father's is passed on to the children), applied to the social organisation of Juchitán as a whole, means that the mother is present in the symbols of the culture as the origin of individual and community life. That in turn means that the *providing*, *caring* tasks of the mother and the needs she serves have a name and are named; and the pattern of significance is, as it were, woven according to these instructions. For example, the production and distribution of food, which are central to women's work in Juchitán, are termed *work* and *economy* (in contrast to here, where many housewives claim "I don't work", and *economy* is connected with industrial production); and women and the distribution of food they have produced themselves are the centre of festive activities. Or another example: needing help is regarded as completely natural and not treated as an irregularity.

WESTERN SOCIETIES HAVE *THE DISABLED*, BECAUSE *HAVING NEEDS* HAS NO CULTURAL STATUS

From this comparison of symbolic orders, it is not difficult to see why the autonomous individual, who is not primarily in need but is instead self-reliant, independent, manages on her or his own, represents the ideal of the patriarchal society. The origin in the mother finds no symbolic representation in the forms of social life (e.g. in language or written and unwritten laws). It is difficult to accept the origin in the mother, and thus oneself as a creature that needs help. But why is it that the autonomous, independent individual finds it so important to reduce people who need support so one-sidedly to their dependence and need of help? Perhaps because people's self-reliance is in fact artificial or only an illusion after all? In order to suppress her or his own dependence, however, the autonomous individual requires a lot of discipline; people must constantly deny their needs and state of dependence. Disability and the way it is dealt with in our society thus possibly plays a role in maintaining the illusion of independence. "The disabled" form the background against which "the normal and healthy" can feel strong and self-reliant (cf. Pixa-Kettner 1981). However, those who *make it on their own* can only stand out in contrast to people who have to rely on others if cultural representation and social acceptance remain withdrawn from the latter due to their dependence and reliance. The stigma of being *disabled* removes the status of being *normal* from needful and reliant people. In a panel discussion, Alicja Schmidt put it in a nutshell. “People say, *You are sick* – because I’m handicapped – *and so you aren’t normal.* Well, isn’t it normal to be sick?”

The severely spastic founder of *Danceability* (a modification of the dance-form *contact improvisation*) also brings home to us the fact that *the disabled* exist because people believe that they are not allowed to need others. When asked in a television interview how he, as a *handicapped* person, could perform such feats [i.e. the dance, B.H.], he responded with another question: “What makes you think I’m handicapped? I can say what I need, can you?”

NOTES

1 Cf. the analyses of Juchitán’s social structure, including: Bennholdt-Thomsen, V. 1994; Holzer, B. 1996. Campbell, Howard et al. 1994.

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DEFINING THE ROLE OF RELIGION AND SPIRITUALITY IN THE LIVES OF PERSONS WITH DISABILITY IN THE FATICK REGION, SENEGAL, AND THE MONO REGION, BENIN

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INTRODUCTION

Over the past two decades, there has been ever-increasing interest in traditional medical practices in general, and specifically as regards their social, healing, ritualistic, religious, and spiritual dimensions. History reminds us that, with the advent of the Cartesian system, local practices have been divided, ridiculed, and repressed through oppressive laws. Despite the *progress* of science and technology, modern medicine is now experiencing setbacks worldwide.

There are several deficiencies in Africa and the third world, among them:

- the lack of sufficient medical and paramedical staff;
- the lack of satisfactory laboratories and paraclinical test facilities;
- the lack of satisfactory logistics and equipment;
- the prohibitive costs of medical services.

The Western world realizes that technology has been going at a pace which is far too fast for *Man* in his psychological, religious, and spiritual dimensions to keep up with. Modern medicine de-humanizes *Man* and involves him in controversial practices. Across the world, whenever a scientist develops a *theory of knowledge*, some logic must found the laws of it. Whatever it is we want to understand about this world has to be molded in abstract concepts and abstract laws. However we need to forsake this kind of conceitedness, for nature abhors being locked up into such theories. We can only have a grasp of nature through images, symbols, rhythms, and sound. Therefore, we are not the ones who command the way in which nature should offer to be understood. We can only guess how nature may unveil itself for us to read its signs. In studying the anthroposophical dimension of spirituality, one can notice that our usual ways of thinking, along the lines of the materialistic mode, which may be valid in the study of the dense, physical plane, are of no avail when we deal with the spiritual levels. We need to build on this first observation and take it into account urgently in order to get closer to our understanding of *Man* as a global and vivid *Whole*. The physical body can merely be understood from the physical world; whereas the subtle body, the body of formative forces or spiritual body, must be understood from the ethereal, spiritual, and cosmological world whose laws are quite different from those of the physical world.

Following the epidemiological and socio-anthropological surveys which were carried out in Senegal and Benin, we will try in this study to expose Africa's viewpoint as regards those specific areas. On the one hand, we will see what Africa's contribution might be and consider how to prepare the Western world to welcome that contribution on the other hand. PROMETRA has had the same concerns over the past two decades and has been working at promoting traditional medicine, as well as ways in which African spirituality and religions impact the evolution of mankind and the world. Our project aims at bringing about a more judicious approach on the part of health professionals both in the U.S.A and Africa, utilizing religion and spirituality in the treatment and rehabilitation of persons with disabilities by means of deeper insight and research into the African experience.

AREAS OF STUDY

The study covers two West African countries, viz. Senegal and Benin, with specific focus on the regions below:

1. the Fatick region in Senegal
2. the Mono region in Benin.

Several reasons lay behind the choice of these regions. Despite the development of their history, from the times of explorers to the current economic expansion, through slavery and colonization, both regions have been able to safeguard their tradition, cultures, religion, and spirituality. The project location in Senegal is quite significant for PROMETRA has been operating there since 1971, pulling all the local healers together into a pyramid-like association. The association now has 500 members and is officially recognized by Senegalese authorities. PROMETRA has also been collaborating with healers and leaders of the cults of Voodoo, Tchango, Babalao, Candomble, Zangbeto, and Kouvito. There certainly is no need to remind anyone that Benin is the cradle of the Brazilian Candomble, the Haitian Voodoo, and the Cuban Santeria. Moreover, the *Communauté Nationale du Culte Vodou du Bénin, CNCVB* (National Community of the Voodoo Cult of Benin), which is recognized by Presidential decree, is a member of PRO.ME.TRA., now a non-governmental organization.

RELIGION

In all cultures across the world, religion is a concept which is only applied by and to mankind. It is one of the basic components of the elements of which man is made. According to African philosophy, the human being is a *Whole* composed schematically of five elements:

- The Physical Element
- The Psychic Element
- The Moral Element
- The Spiritual Element
- The Mind Element

The third element, the *Moral*, is the religion of man. This is where the difference between man and animals lies. This is obvious: the human being is the only creature capable of malice for no reason.

Therefore, there is a need for something to stop this innate aggressiveness. It is usually said, "The Devil dwells in religions, the criminal in jail … ." In Africa, there exists a multitude of religions but their symbolisms, rituals, and practices are characterized by a certain commonality as though they derived from a common source. This is the reason why, in our definition, we refer to *Religion* rather than religions. In his work Cosaan, Reverend Henry Gravrand appropriately wrote that the African religion in general is based on the personal and/or collective transcendence of sacred nature (1993). The initial data will be regrouped around three attributes of transcendence. Transcendence is both life and source of life.

1. It is communication: by means of symbols it becomes close and accessible.
2. It is participation: it creates among all beings in the universe a community of destiny.

Transcendence is Life

Life is a dynamism which is transmitted by the transcending power to animate material and spiritual organisms throughout the duration of their cycle. This definition deals with the origin, nature and cycle of life.

Origin: Life comes from personal and/or collective transcending power which creates and renews energy in the cosmos, endlessly.

Nature: Life is energy which animates a material or spiritual autonomous organism endowed with qualities proper to its kind.

Cycle: Life is a dynamism of cyclical character, susceptible to energy reinforcement or loss.

According to Lalaye, life originates from the sacred and makes of the person a sacred treasure.

The Nature of Life

Life is a dynamism which allows the being to emerge into existence according to the nature of the species. Life is perishable energy for material beings, but imperishable for spiritual entities. In the middle of the 20th century, Rev. Placide Temples brought into Philosophie Bantoue a new answer to a new question: the concept of *Vital Power*. A being is power. He is, in order to be power. The nature of life is not limited to a dynamism of fertility, growth, and intense communion with the other. It also requires physical and mental health, as put by Memel Fote: "life and health, life and abundance go hand in hand". Hence the importance of health preserved and recovered through healing (Temples/Fote in Gravrand 1993).

The Cycle of Life

All life in the universe is cyclical: movement of the stars, days, seasons, menstrual cycles, and animal or vegetable reproduction cycle ... African philosophy represents life in a cyclical form. Man is perceived in this huge movement of life, which derives from transcendence. The cyclical movement takes place in two main phases:

- A descending phase characterized by a loss of vital biological, but not spiritual, energy.
- An ascending phase of the cycle characterized by essential times allowing people to strengthen their vitality. The source of vital energy, transcendence, constantly procures vital reinforcement. So do other entities in their turn: the family which takes care of the young sprouts entrusted to their experience and care.

The matrilinear clan is the largest entity and the most likely to help its members in any situation. The ancestors living in the beyond are an integral part of the clan, since the same shared life flows through the body of the living and the dead. The latter use their mediatory and secondary, but always efficient, power in favor of the living who extend ethnicity from the beyond. There exist essential times allowing the youth to reinforce their vitality:

- Baptism
- Circumcision
- Initiation
- Marriage

Transcendence Is Communication

Transcendence is communication because it is immanent in the world. The sacred is in daily life, the human body, the tree with strange shapes, animals, ant-hills, etc. It is a passage of the supernatural through the natural. Through the religious, the world is perceived as a *Great Whole* where everything is structured on the basis of a common finality. The Great Whole extends into two dimensions: the visible and invisible. The visible dimension has several levels of existence: human, animal, vegetable, and mineral. In each of the levels above, beings have a material support as well as a spiritual element. The latter, the *spirit* of the visible beings, is to be distinguished from the invisible beings likely to occupy them momentarily as a meeting place with the living. A snake can be the support of an ancestral spirit: *Pangool* among the Sereer, *Dan* among the Popo. He can nonetheless make use of his own spiritual being.

The invisible dimension comprises:

- the Supreme Being;
- intermediary beings between the Supreme Being and humans; and
- the other spiritual entities.

There is no absolute separation, rather continuity and compenetration linking the visible and invisible dimensions. There is only one being in the world for the Popos and Sereers and the structure which comprises both aspects, material and spiritual. This general world structure reproduces itself at the level of each being, which possesses an outer aspect and an inner content. Man is like grass. The Popo and Sereer vision of the world will be better grasped when the hierarchical structure of the whole reality is examined. Above the Universe, there is the personal transcendence. Intermediary beings exist on the ontological level and that of action and man is located at the junction of the visible and invisible. Animals, plants, minerals, etc. are all actors in man's adventure.

Contrary to the religious Hebraic thought, where the absolute transcendence of *Yahweh* is the guiding idea of the Old Testament, the Popo religious idea – *Yahweh* – or Sereer *Pangool,* perceives the Supreme Being as immanent of His creation. According to these cultures, man has three essential means to communicate with spiritual powers:

- the Word: the power of the speech
- the Rhythm: the power of movement
- the Symbol: the power of the image.

Through the combination of the three powers, man plays his role as head of the cosmic adventure bridge, by way of poetry, dance, and magic. These different elements contribute to the creation of several rituals allowing for communication with transcendence.

Transcendence Is Participation

The whole life of the African spirit is perceived as participation in a transcendent dynamism. Participation brings about a fundamental and vital unity, and interdependence among beings, due to their common source of energy, emanating from transcendence. This has two implications. On the one hand, there is a generalized parenthood among all of nature's elements. Nature's laws are thereby attenuated or annihilated through magic and religious techniques, that is, by means of the sacred. Hence one can observe cases of bilocation, levitation, split personality, or metamorphosis into an animal. On the other hand, man claims that he himself enjoys immanence with nature, which allows him to play a preeminent role in the cosmic adventure. He is not, and this is no secret to him, the first source of Transcendence, rather the main user and caretaker in so much as he can manipulate the sacred. To say that transcendence is participation is to enunciate a truth. The sacred and vital energy spring from the transcending being and run throughout the material cosmos, the human beings and spiritual entities. Given this communal participation in transcendence, African thought believes in an intimate link between man and his environment. Thus, he keeps dynamic relationships with the mineral, vegetable, animal, and human world. Furthermore, he keeps dynamic, active, and passive relations with the triple environment surrounding him, that is the cosmic, the social, and the sacred.

- Relationship with *air*
- Relationship with *fire*
- Relationship with *water*
- Relationship with *earth*
- Relationship with *trees, animals, Pangools, Yahweh, etc.*

Such different relationships mean a great interpenetration within the group. The African art of living is participation, the deep communion with the other, and the horizontal as well as vertical groups. This kind of participation is as vast as possible. It surpasses groups actually brought together to expand and grow into the Cosmos.

SPIRITUALITY

According to the Larousse dictionary, spirituality is “the quality of that which is spirit. Spirituality of the soul for instance”. The genuine traditional African can differentiate perfectly between the image of himself and the very image he is to represent. He therefore accepts the idea of Man as a *Great Whole*. Indeed, according to philosophical, sociological, anthropological, metaphysical, and cosmological viewpoints, human nature is a *Whole*, with regard to that which is earthly (natural), extra-earthly (supernatural), and cosmogonic. Reduced to its simplest expression, the Whole has five basic elements.

1. The Physical
2. The Psychic
3. The Moral
4. The Soul
5. The Spirit

The moral has just been defined as *the religious* dimension of Man which can be compared to a need to constrain Man’s innate aggressiveness. We have dealt with this need as a way of being, based on the three attributes of Transcendence: life-communication-participation.

As far as man’s five basic elements – the physical, psychic, moral, soul, and spirit are concerned – it is important to underscore the fact that these are not separate entities. Actually, a seamless inter- and compenetration exists among them. The fifth element of this *Whole* is the great Spirit made up of smaller spirits which are known and present several levels. Furthermore, the African family is composed of horizontal and vertical families.

- The horizontal family is made of the father, mother, aunts, uncles; brothers, sisters, children; grand-children, living grand-parents, nieces, cousins, etc.
- The vertical family descends from the founding ancestors to the future descendants.

In this sphere of influence, the spirit plays, among others, a cementing role and has, at the individual and collective stages, many categories or levels.

The First Level Spirits

These are the spirits of the deceased ancestors. According to the African philosophy, the dead are not dead and reincarnation is a deeply held belief. Africans believe that death is not an end in itself; it is like a closing door. There is an opening door to each closing door and people are subject to this back and forth movement because human nature is *a work in progress*. It has to evolve toward something better. The cycle of one's life being short, in order to perfect himself, man needs to participate in a number of experiences. There exist *Abikou* experiments among the Popos in Benin and the Sereers in Senegal which make one believe that, before one was born, one was already living. The experiment is carried out on women said to have *cursed uterus*, that is women who experience miscarriages or stillbirths continuously. At the third stillbirth, prior to the burial, the elders perform a ritual and make a mark somewhere on the child's body. Some time later, the mother gives birth to a child named *Abikou* bearing the same mark. This child does not die at an early age.

Another experiment leads to the belief that death is not the end. The experiment is carried out solely by a Sereer Family called Samelle. The latter lives in a small village at Diouroup, 140 kilometers from Dakar, the capital city of Senegal. The Samelles are human beings, just like ourselves, who play an intermediary role between the living and the dead. For example, someone dies without leaving a will. On his way to the other world, he visits the Samelle, leaving him with a message for his family of buried money under such a tree, or a white horse lent to such a person, etc. On their mission, the Samelles are dressed in red and never wear shoes. They never use any means of transport regardless of the distance. When they get to the dead person's house with their small drum under their arm, they deliver the message of the deceased, which always proves to be true. Most of the time, the Samelle's message is so rapidly delivered that he is the one who first informs the family about the existence of the corpse in the room. Up until now, the Samelles have always been buried in the trunk of a baobab, a big tree of the Sahel region. Thus, the first level is comprised of the Spirits of the dead.

The Second Level Spirits

These are the spirits which govern the world. This is the level where spirits consult one another to impart to the world and human beings the movement, giration, cycle, and primal energy without which no life is possible.

Obviously, despite the progress made in science and technology, not a single laboratory in the world can establish a biological difference between an organ from a living human and the same organ from a corpse! That is because the only difference between the living and the dead lies in the energetic nature guided, among others, by the 2nd spiritual level.

Science is still far from forecasting the weather with any precision beyond 72 hours! If, on the earthly level, we are so technically well advanced, we must acknowledge, factually, how far behind we still are spiritually, still delving in ashes! At least, with regard to certain civilizations.

The Third Level Spirits

This is about a coherent and well-ordered repositor of universal science, knowledge, and memory. The 3rd level is usually called *Morphic Resonance.* It is a kind of collective memory. No science in the world can prove that there exists a memory center in the human brain. In fact, the human memory is outside the individual. It is exogenous to his physical manifestation. Some cerebral neurons might play the role of a transistor connected to the collective memory. The internet network is a technological achievement which is based on similar principles. Unfortunately, the latter uses reasoning which remains a source of errors. In the Internet network, each user puts there what they hold for the truth from hypotheses and starting points for thought which are often narrow and shallow. We are too well aware today of what has become of some of yesterday's affirmations or discoveries!

Some master mediums called *Saltigui* among the Sereers of Senegal and *Bokonon* in Benin can, through some rituals, communicate with the 3rd level and make predictions which prove true over several years. As a matter of fact, a Saltigue during Khoye (a public prediction session) can predict the date of the first rain, the number of rains through the year and in his village, the quality of the season, possible epidemics, etc. The 3rd level reigns over people's collective memory after it has *filtered* and *sieved* it.

The Fourth Level Spirits

This deals with a group of 256 spirits which are well known, codified, classified, and studied within an African science called *Fa*. The latter is common in the geographical area spreading from Ghana to Nigeria through Togo and Benin. This West African area covers the former Popo-Adja Empire. *Fa* is *Afa* among the Popos, the Minas, and the Pedas; *Ifa* among the Yorubas; *Ofa* among the Gouns, and *Fa* among the Fons. The difference in names, which varies from ethnic group to ethnic group, changes nothing in the symbolism, ritual, science, and instruments that allow the Bokonon to access the Kpolih or spirits. Some use *Fa* as a geomantic system dealing with the 256 spirits to predict through the oracle to enlighten an individual, a group of people, a community, or a society. There exist 16 major spirits represented by signs. The 240 minor spirits are the combination of major signs amongst them. The 4th spirit level is a very large domain which can be the subject-matter for further studies. There is a need to clarify the fact that each individual enters the world through one of the 256 spirits no matter what the color of their skin is.

The different levels of spirit so described are an integral part of man. It is man's spirit which remains the fifth element of the *Whole* we are. The *Whole*, as already said, is connected to everything, whether natural, or supernatural, or cosmogonic. This connectedness is also insured by other Spirits.

The Other Spirits

The other spirits are immanent in what could be called Primal Spirit. God's first breath or the Great Universal Architect's breath makes the primal Spirit. *Primal* for being primordial; primal for being *First*. According to African myths, the primal Spirit gave *birth* to the other four master primal Spirits of life's primordial elements.

1. Master primary Spirit of *Airs*
2. Master primary Spirit of *Waters*
3. Master primary Spirit of the *Fire*
4. Master primary Spirit of the *Earth*.

The entire genesis of life on our planet comes from these primeval elements, themselves deriving from Primary Spirits and engendered by the *Primal Spirit*. This is why, at its core, African philosophy holds that all people, all living creatures originated from a common source and have got to move, according to the duration of the cycle related to their species, towards that very same source. Spirits herein referred to as *the other spirits* are the cement between all the creatures of the universe and plunge them into a community of origin and destiny.

THE PERSON WITH A DISABILITY

The notion of disabled person, that is a diminished person, is a notion which does not exist in African tradition, at least in the geographical areas the study deals with. It could not be otherwise since the notion of disability is concerned with both the physical as well as the mental. Africa considers the person as a whole, a great whole stretching toward the *primal* source, towards the Héréhéréli say the Bambaras, Tantin according to the Popos, Totodji according to the Minas; N'Kon say the

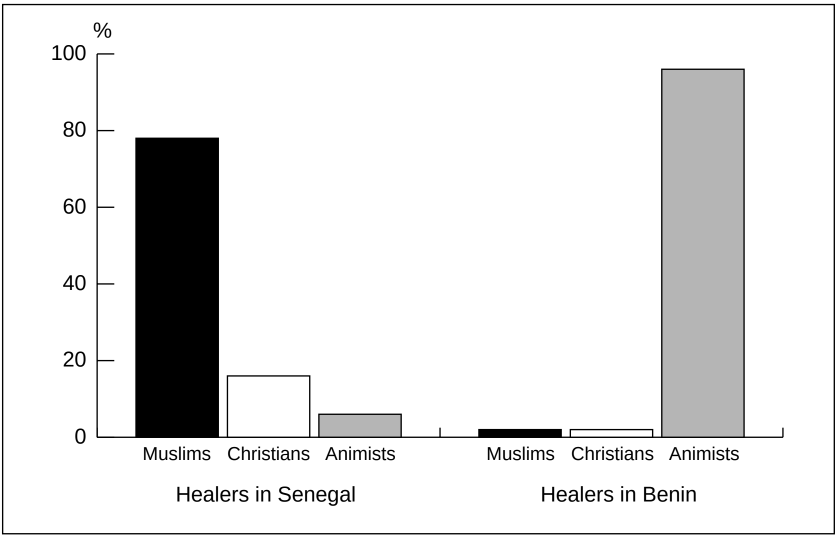
Fons and Gouns; the Wolof use the concept Ndial-Been; the Sereers using Mberadon-na.

The word *handicap* has been imported into Africa. The word objectifies a person, which is contrary to the African framework of thought in a very fundamental way. If, at all, it exists in Africa, it is primarily with regard to the task, the religious and spiritual mission of the individual vis-a-vis his community. Indeed, a woman, for example, who does not show any physical or mental alteration, no matter how beautiful she might be, can be considered as diminished due to her being *sterile*. This defect is reason enough for her to be rejected by her own. Legend has it that God made the woman and said, "Men can die henceforth, life will continue on earth." Thus the woman has, among others, the mission of procreation. Failure to fulfill this divine mission is perceived more as a *handicap* than the case of a woman suffering from the aftermath of polio as long as she is multiparous.

- *Some disabled enjoy a great deal of respect from their community*
- *Some disabilities are a source of fortune*
- *Some disabled are messengers*
- *Some disabled are a necessity*
- *Some disabled may not live with other people*

The persons surveyed via the questionnaire have been selected on the basis of the census lists of the total number of persons living with a disability and the total number of healers in the relevant areas. People caring for disabled persons have been selected after identification of persons living with a disability. Overall, a questionnaire was used with 877 healers (717 men and 160 women) living in Benin and Senegal. The quantitative questionnaire interviewed a total of 347 (178 men and 169 women) persons with disabilities, 295 in Senegal and 52 in Benin. The questionnaire addressing people in charge of disabled persons was applied to 305 men (55 %) and 246 women (45 %), that is a total of 550 persons (468 in Senegal and 84 in Benin). Interviewed persons living with a disability are either blind or physically challenged. The number of people in charge of disabled persons was higher than that of persons with disabilities. This is due to the fact that some disabled persons (minor children, deaf and mute persons, mentally challenged ones) were not interviewed while people caring for them were.

Table 1: Distribution of Healers according to Religion and Country



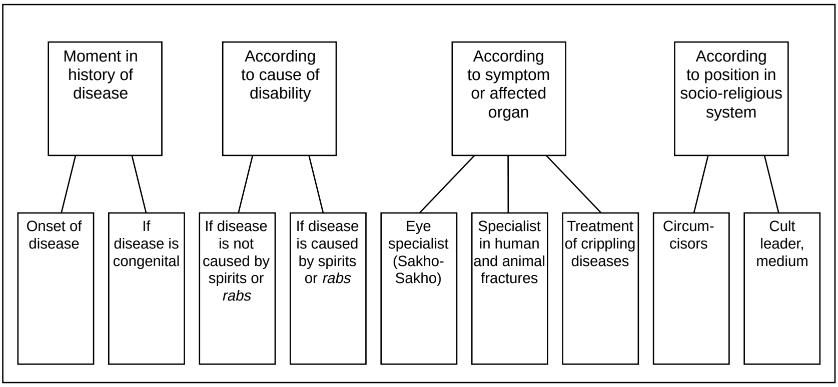
Just as is the case within the general population, polygamy is predominant among them; usually, their educational level is low. However, in the Benin sample, there is one healer who had higher education. Healers we have interviewed say they have treated various types of spastic, physical, or mental disabilities over a relatively long period of time. One of them declared: "I've been treating disabilities for over 20 years now." Another one said: "I have a 39-year experience, treating disabled persons; I have dealt with all cases." Some are quite willing to talk about some of the cases they have treated: "Twenty-three years ago, I cured 4 male disabled persons who had not been able to walk for over 6 years."

The Types of Healers Met

Analysis of interviews we have conducted with healers reveals the existence of different types of healers according to a typology which is mainly based on the following criteria:

- type of disability, affected organ, symptoms identified;
- origin or cause of disability;
- moment in history of the disease.

Table 2: Type of Healers and Types of Disability



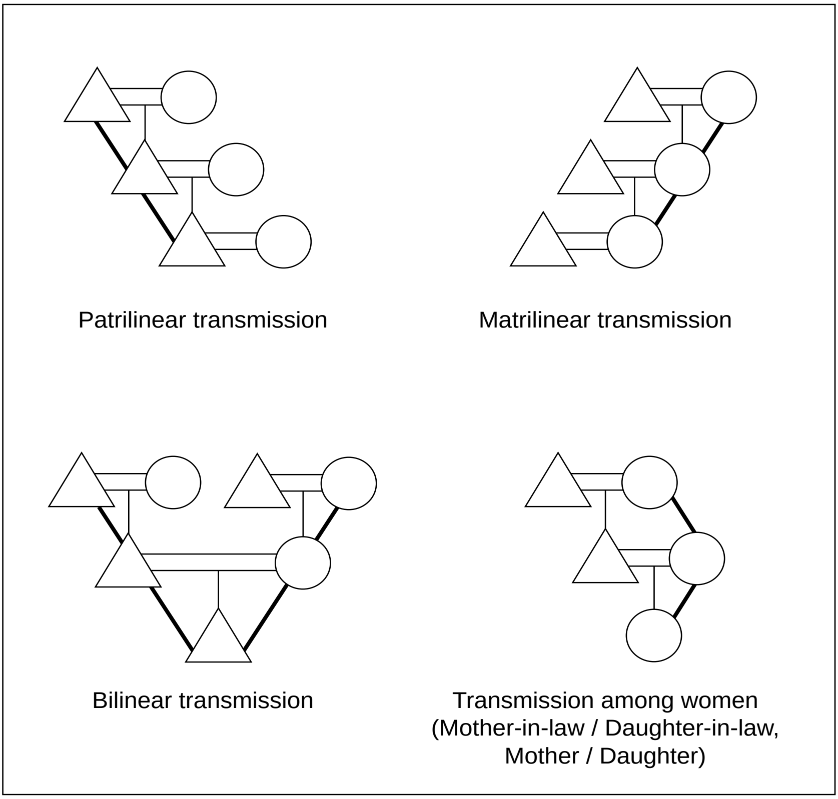
As regards the history of the disease, two interviews indicated that the healers involved only treated disabled persons at the very start of the disease. They had no competence for long-lasting or congenital disabilities. One interviewee indeed declared: "I treat mentally disabled persons at the onset of the disease." Another one insisted: "I only treat non-congenital blindness." In most cases, healers define themselves in relation to the cause of the disability. For a number of healers, only when the cause is not natural but mystical or occult can they intervene. Many of them have made declarations similar to the following: "I can treat any type of mental or physical disability caused by a spirit"; or "I can treat certain types of disabilities caused by spirits (Rabs) which paralyze, reduce, or misshape the lower limbs of individuals." For some healers, the field of expertise is determined by the means available to them. A healer who can benefit from the intervention of spirits can also treat disabilities caused by those same spirits: "I treat mentally disabled persons who are under the power of the spirits (Rabs) who can be neutralized by the Tuur."

Sources of Wisdom

Healers often declare that the wisdom which helps them treat persons with disabilities is a gift inherited from their parents. In certain cases, inheriting the wisdom means inheriting the cult of the ancestors. Thus, assuming the responsibilities of caretaker of the cult upon the death of the predecessor coincides with reception of wisdom. However, transmission of the wisdom through legacy is subject to rules which are beyond the control of humans. Only spirits of ancestors can allow such transmission. Thus, the ones transmitting their wisdom choose among potential recipients the person most suited – morally, intellectually, mystically, and spiritually – to be accepted by the ancestors. Clearly, the spirits of ancestors also give signs allowing the best choice possible among potential candidates: "My sons can inherit my wisdom but it all depends on the way I behave toward the cult of ancestors ... Before I pass away, the heir to my wisdom will be revealed to me." Sometimes, the choice of the spirits is commanded by a special relationship they maintain with the recipient. When that occurs, they enter into direct communication with the person and inform them of the specific activities they have been chosen for. The following account falls into that category: "The spirits decided to endow me with the secret of mediumism. They kept jangling the clatter of cowries in my mind and ordered me to practice as a medium. The spirit (Rab) delivers the messages through my performance."

Some interviews reveal wisdom genealogies which take up matrilinear or patrilinear lines. Thus, regarding patrilinear lines for instance, a Senegalese healer declared: "My wisdom is a legacy of the Sañaaneem lineage. I am the eleventh heir of our lineage wisdom." Similarly, still another one summed it up in these words: "I inherited my father's wisdom; he himself inherited his from his father who had inherited the same from his own father. Overall, there are 9 ancestral healers in our family." Likewise, some women healers testify to their matrilinear lineage: "I inherited my wisdom from my grandmother; I am caretaker of the cult. This is a legacy of my maternal lineage." Another woman said: "I inherited my wisdom from my mother. I will take up her role when she dies as caretaker of the cult and medium." However, filiation modes do not exclude one another because a bilinear transmission is also possible: "I inherited my wisdom from both my father and my mother; my wisdom is a legacy of my two lineages." Moreover, the legacy is not just a matter of direct parenthood; some relationships through marriage also participate in the transmission. The following account is quite clear: "My father's mother used to treat this type of physical disability. My mother inherited the wisdom and passed it on to me to ensure it would stay within the lineage."

Table 3: Modes of Wisdom Transmission



Patrilinear transmission

Matrilinear transmission

Bilinear transmission

Transmission among women (Mother-in-law / Daughter-in-law, Mother / Daughter)

In other interviews, we have learnt that wisdom transmission is linked to totemic relationships whereby a founding ancestor was entrusted with certain kinds of wisdom by an animal. “In the beginning, our wisdom was revealed to us by wild animals, specifically by a gorilla,” said one healer. For some healers, wisdom is acquired as a counter gift, a sort of compensation for a pain or a painful sacrifice. “My wisdom is innate. My mother was childless for some time and my grandmother consulted a healer. My mother brought me to life thanks to two horns and a few incantations. I did not go anywhere to learn my job. I was born with my wisdom and the Rab taught me the rest.”

For certain healers however, wisdom is endowed by the astrological sign under which they were born. For this Benin woman healer for instance, her wisdom lies in her ontological relationship with the star of wisdom: “I was born under a star of knowledge and wisdom. I did not have to learn, my star bestowed it to me upon my birth. As I get older, I find the way.” But in most cases, legacy of the wisdom is associated with an apprenticeship which completes the initial source of knowledge. “The legacy always goes with apprenticeship. When you have a child, you transmit the wisdom to him/her so that they can take up after you.” Another healer explained that he was a wrestler: “Part of my wisdom comes from the marabouts who cared for me, the other part is from my father.”

Apprenticeship comes from several sources, the most frequently quoted ones being the following: Sources requiring journeys. It is the case when a healer says: “I have also traveled to increase my knowledge with other masters.” Another one said: “I went as far as The Gambia to increase my knowledge.” In Benin also, other sources of knowledge are sought outside of one’s lineage or community. Reference is often made to an elderly person or cult leader. Thus a woman healer declared: “I had my apprenticeship with my maternal grandmother.” Another interviewee from Benin explained: “We had our apprenticeship with the elected chairperson of the Vodonon Cult community of Benin. He taught us a lot.” Yet another said: “I went to study with my grandparents, namely my grandfather.”

Other sets of interviews indicate that the main transmitters of wisdom are persons who are in touch with the religious power, such as the marabouts, or with various other fundamental elements of nature: woodcutters with the vegetable realm; hunters with the fauna; or the Jogomay, master of the waters. One interview thus revealed: “I have also learnt from marabouts or other wise people; among them are Ma-Ansu of Silmang; Sëriñ Baara Silla, my marabout, Seex Juuf, my grandfather in Mbaamaan.” Another interview gave the following details: “Amadu Buso is a hunter from Jowal who taught me a great deal; Bira Mbuus, a hunter from the Casamance region was also my master, as well as Yaya Diba, a Socé from Bounkiling. My fourth master is Jogomaay, from Ngothielene.” However, whatever the form through which the healer received their wisdom, the latter seems to ultimately depend on God. The wisdom may be acquired or innate, inherited or learnt, but ultimately it is mostly influenced by the ancestors and the spirits who participate in the selection of the person elected to receive the wisdom. Yet, interviewees declared that such intervention is not, in itself, independent of God.

Social Representations and Interpretations

The analysis of the qualitative data we have collected shows that the disability is generally described not as the result of a long process but rather as a sudden phenomenon occurring unannounced. The mother of a disabled girl thus declared: "My daughter would suffer some fits from time to time. We used to take her to the hospital. One day, she fell off the bed and has been limping since then." Several interviews indicated that the disability occurred at the same time as or following cataclysms or events which at first seemed to stem from ecological phenomena or daily social or religious activities. A blind woman thus explained: "I became blind in my teens. One day during the peanut trade season, I was at the warehouse when suddenly a piece of dust got into my eyes. They started swelling and bleeding. I've been blind ever since." Sometimes, human actions occur concomitantly with the appearance of the disability. One woman told us the story of her sister: "When she was born, only one of her eyes was valid. One day, one of my brothers, who was also very young, threw a mango fruit at her from the mango tree. The mango broke her other eye and she turned completely blind." This account sounds very similar to that of another disabled person who said: "Only one of my eyes was valid at birth. As I was playing with my twin sister one day, she threw a stone which hit my valid eye. I was five years old then and have been blind ever since." Some interviews indicate that the disability occurred in a physical or social environment interviewees highlighted. A spastic woman thus declared: "One day, when I was still a baby, my mother put me down in a crowded public square. Suddenly, I got scared, my hand and my foot could not function anymore and I was believed to be about to die because of the unbearable pain."

In interpreting the causes of the disability, interviews have shown that the events or phenomena associated with the occurrence of the disability are virtually never viewed as being unique. There actually is a chain of causality which leads to the acts, events, or backgrounds associated with the disability being, in turn, determined by a series of causes relating to different ontological levels. Thus the dust that entered the young girl's eye and blinded her is a mode of existence or movement of one of a living dead *Qonopaaf*. In most of the interviews, there is an articulation of events associated with a set of causes we can put into four categories:

– the protective spirits *Rabs* who, by nature, have special ties with the individuals, families, or lineages; humans communicate with the Rabs, namely through the ancestral cult *(Tuur)* and renew their alliance with the spirits. Such an alliance must be permanent and based on faithfulness;

- the evil or dangerous spirits: they have no special relations with human individuals, families, or lineages. They may however establish occasional, limited alliances with humans;
- the evil spell provoked by human actions when someone resorts to mystical or occult means to hurt an individual, their family or descendants. One healer thus said: "We human beings are capable of malice and we can actually cast an evil spell on somebody to disable them";
- God is also considered to participate directly or indirectly in the advent of the disability.

The causality related to the protective spirits *Rabs* underscores the conception according to which the Rab reacts when the special relation established with an individual or a group of individuals is broken due to a violation of the rules guiding the relationship. This occurs namely when a social or totemic prohibition is trespassed or when the practice of the required cult is abandoned. In Benin, it is believed that the spirits of the Voodoo may afflict with dementia some persons whom they are actually supposed to protect because the latter have been found guilty, through their attitudes and behavior, of a breach of the alliance established with the spirits. During the transmission process, the Rab may involuntarily cause the disability of the recipient. Interviews reveal that, if the weight of wisdom the Rab is to transmit to the elected person is too heavy, due to the latter's physical, moral, or spiritual capacities, they may fall sick and be disabled.

The intervention of evil spirits often happens during an encounter which is generally described as being fortuitous because the man has violated the holy places in time and space, while those places are prohibited or viewed as dangerous. The mother of a disabled boy thus confessed: "Rumor has it that the spirit of the Bakojunga holy places caused my son's disability." In trespassing upon a sacred place, the person may commit a serious offence against the spirits and thus provoke their revenge. A blind man thus explained: "I was on my farm and I fell down a tree. In fact, the tree was the dwelling of a Djinn. I burnt up the tree and, as a result, two or three offspring of the Djinn died. According to healers, the Djinn made me blind as revenge."

The disability may also be caused by evil spirits who like acting with malice. In this case, people believe it to be Satan's *Seytaane* doing. Similarly, supernatural man eaters *Dëmm* may also provoke the disability of a person if they fail to eat them. Moreover, there are several relationships with articulation between the protective spirits *Rab*, the evil spirits, and the evil spells humans cast on others. The evil spell cannot be operational unless used in conjunction with the participation of the spirits. One healer revealed: "There are some Rabs who are on good terms with Satan and they are paid by human beings. It is even possible to turn your own Rab against you and into an enemy. Rabs receive as a compensation some oxen, horses, or even human beings sometimes."

Similarly, divine or religious causes are mentioned in various ways. For instance, some persons with disabilities believe that their condition is a divine punishment because they failed to respect a religious prescription. One of them said: "My disability is a sign of destiny. In the past, I used to climb the baobab tree to pick up some fruits and everything went fine. My disability occurred the day it should have occurred, that is on Sunday, 19th or 20th of March, 1995, when I fell off the baobab. This was the fasting period, I was not fasting and Sunday is a day for rest, I was not supposed to work. So, when I fell, I immediately knew that it was a punishment from God."

The will of God is also mentioned as the main cause determining all other causes. A key informant thus said: "There are diseases which fall within the province of God and others which come within that of spirits, be they protective or human wizards; but only if it is the will of God will the diseases falling within His province occur."

However, some interviews explicitly deny the intervention of spirits and Rabs, considering only a natural (biological) cause. Even in this strictly naturalistic interpretation mold, God is viewed as the ultimate cause of the phenomena which happen along the lines of natural processes.

Reference to God sometimes leads to the thesis according to which a disease is an ordeal God imposes on us to test the solidity of our faith. This ordeal participates in relations of necessary balance which allow happiness to come after suffering, the former indeed even being a prerequisite for the latter. A healer thus declared: "Phenomena fall within the province of God, happiness as well as suffering. Both are part of the life of each individual. There is no suffering without happiness and vice-versa. One cannot be happy everlastingly. The sea has high tides and low tides, and the shade under the tree is not there all the time."

Similarly, sending a disability onto a person is often considered as some sort of *sacrifice* which is meant to protect the community from even greater adversity. In certain cases, a disability occurs when a person or a family enjoy privileges such as wealth, power, etc. which place them in a higher position than the rest of the community. The ordeal (Nattu) that God places in the face of an individual is also integrated in a logic of interpretations which assumes that all that happens to the individual was due to happen. “Man’s fate is pre-established, while in the mother’s womb. God may act through a Djinn or a Rab, or through a wizard. A person may fall accidentally from a tree but it had all been decided upon by God from the very beginning.”

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FOLKLORE BASED ANALYSIS FOR A CULTURE-SPECIFIC CONCEPT OF INCLUSIVE EDUCATION

Joseph Kisanji

INTRODUCTION

Disabled People's Organisations, parents' organisations and professional groups and individuals have, over the past decade, been grappling with the concept of inclusive education and how it can best be implemented. The United Nations and its specialised agencies have provided the framework for its planning and implementation (UN 1994; UNESCO 1994) but also fuelled much criticism. For instance, Haskell (1998) refers to inclusive schooling as "contemporary cultural imperialism of western ideologues". Indeed, many studies of inclusive school practices have so far been carried out in the North. Unfortunately, political, social, economic and cultural conditions in the countries of the North are markedly different from those in the South. To what extent, then, is the concept of inclusive schooling/education relevant to the South? Should planning for inclusion follow models of the North? These are broad and complex questions, which we cannot ignore if we are to learn from cross-cultural perspectives. The purpose of the study reported here was to determine community attitudes towards persons with disability in Tanzania as a basis for exploring the existence of inclusive practices through an analysis of the community account of its own action, as contained in fireside stories and proverbs.

CHOICE OF FOLKLORE FOR STUDYING ATTITUDES AND INCLUSIVE EDUCATION

Impairment is a human characteristic; it knows no bounds in terms of time-space, geographical location, social or economic status and age-band. The currently available statistics on the prevalence of disability in different parts of the world are a product of guesswork because perception of disability is culture-bound, and culture-sensitive assessment instruments are yet to be developed. However, despite this cultural dimension, interpretation of attitudes and beliefs relating to disability and persons with disabilities in different parts of the world has been based on foreign value systems. For example, African attitudes and beliefs were being interpreted within a Western frame (Ingstad 1990; Kisanji 1995). Research on perceptions and attitudes are important particularly at a time when national governments are planning and/or implementing Education for All (EFA) and inclusive education for different groups of people previously excluded. Schools as social organisations (Fullan 1991) are most likely, despite international trends and rhetoric, to respond to the needs of these groups in ways that reflect community perceptions and attitudes. Since perceptions and attitudes also influence the content and process of informal and non-formal education, studying them could shed light on what processes and materials the school could adopt or adapt to ensure cultural relevance.

Previous studies in African countries have employed survey methods. However, in this study, I explored the manner in which language was used metaphorically in the folklore in relation to people with disabilities with a view to teasing out underlying perceptions and attitudes. Lakoff and Johnson (1980), in their book *Metaphors We Live By*, seem to provide the most systematic and detailed analysis of metaphors and the way they are used in everyday life. They argue that a community's system of concepts is metaphoric and, therefore, the people's language and behaviour is organised metaphorically. As the "essence of metaphor is understanding and experiencing one kind of thing in terms of another" (ibid.: 5), disability and persons with disabilities in the folklore (proverbs, folksongs, poems, stories and riddles) studied have been taken as metaphoric structures and concepts. My choice of metaphors as the component of culture through which I could study community attitudes and perceptions of disability in Tanzania was also based on the understanding that language is both a vehicle for acquiring the content of culture and an aspect of content in itself. The importance of language in a cultural context lies in the fact that it is the vehicle for transmitting culture between members and from one generation to another (Kuhn 1966). Language also fosters social cohesion and a people's identity (Diop 1991; Crystal 1987). It was, therefore, possible to analyse the metaphoric use of language in order to examine attitudes towards people with disabilities and to tease out any possible processes and structures relevant to inclusion.

Methods

Folklore provides the raw material for explaining a community's behaviour towards one another or one section of a community towards another. Since it is metaphoric and embedded within the day-to-day life, folklore can also be considered to provide the community's account of its actions in a way that is intelligible and justifiable to its members. The aspect of community life under investigation was disability and, as such, through folklore, the community was accounting for its actions in disability-related social episodes. With this perspective in mind, my approach to data collection and analysis was what Cohen and Manion (1994) refer to as ethogenic. Taken as community accounts, proverbs, sayings, riddles, folksongs, poems and tales which carried notions related to disability were collected from Tanzania. The method used in collecting data included documentation and interviews. A manual literature search for the period 1935-1990 was carried out at the University of Dar es Salaam, Tanzania, to identify disability-related folklore in the form of proverbs, riddles, songs, poems and tales. Interviews were also conducted with tribal elders (N=44), primary school heads (N=10) and teachers (N=45) to gather the folklore. The data, collected between 1989 and 1991, were content analysed and thematically arranged by type of disability to determine the disability characteristics and by meaning and usage to provide a basis for understanding the folklore's surface and deep meanings. The thematically arranged proverbs, songs, poems, tales and riddles were circulated during 1994 to 11 Tanzanian students at the Universities of Bradford, Cardiff and Manchester in the U.K. to verify their meanings and usage as well as to elicit their contributions to the disability-related folklore. A few additions were made, especially with regard to songs and tales. The content and editorial comments received were incorporated into the initial analysis. Findings based on proverbs have been reported elsewhere (Kisanji 1995). Songs, poems, stories and riddles were not included. This paper is based on the thematic analysis of all aspects of the folklore, except poems, collected up to 1994.

Results

This study presents a composite pattern of attitudes resulting from the content analysis of the folklore. The results of the study are reported according to the themes which emerged during the analysis. The first part provides a summary of the findings in the thematic analysis of proverbs reported in detail elsewhere (Kisanji 1995) and of riddles, songs and stories which have not been reported before. In the second part, I present a story to take the reader through the process of analysis and to show the educative content of the folklore.

Perception and Attitudes

When the data were initially confronted, they were categorised on the basis of the major traditional impairment areas. This analysis was informed mainly by the global historical trend in attitudes towards persons with disabilities identified in literature (Miles 1983; Ingstad 1990a; 1990b). In this trend and pattern analysis, the data were arranged according to themes which emerged from the folklore's surface and deep meanings. Initially, four main themes emerged, namely 1. disability characteristics, 2. disability in various aspects of community life, 3. attitudes which show persecution (cruelty), and 4. attitudes which show accommodation, equality and human rights. Four main findings could be discerned from the thematic analysis. First, literal translation of the folklore from the community languages to Kiswahili and/or English did not express or contain a generally inclusive category similar to the concept disability. The folklore referred to the specific impairments of blindness or partial blindness (or one-eyedness), deafness, physical impairments, intellectual impairment, behavioural difficulties and mental illness. The second finding was that the characteristics of the impairments which appeared in the folklore were similar to the scientific descriptions. However, the folklore does not concern itself with specific points of lesion in the body other than the body part affected and the limitation imposed by the impairment.

One of the key attitude areas revealed by the folklore was the common understanding that, whatever their causes, impairments were part of human nature; any person could be impaired at any time during life, whatever one's socio-economic status. However, despite the impairments, affected persons were usefully contributing members of their community or could be so if given adequate training and support. The fourth finding was related to the unidimensional reference to attitudes towards people with impairments. This approach to attitude analysis seeks to find out whether community reactions were either positive or negative, an orientation which has influenced the use of such measures as the semantic differential scales. All the 11 students to whom the folklore was referred for authentication, when asked which of the folklore items were positive or negative (specifically which ones indicated cruelty, unfairness or were dehumanising), pointed to only three proverbs as negative. The rest of the folklore was considered positive. The folklore collected later did not fit into the negative theme. In addition to these four findings drawn from all aspects of the folklore examined, stories also revealed other attitude areas. In some stories a subliminal connotation was evident. The person with impairment was portrayed as a hero. This portrayal may be based on the community's uncertainty about the cause(s) of the impairment and, therefore, the belief that such a person had special powers which could not be understood by people without impairments. The stories collected also showed that persons with impairments were capable of developing high self-esteem and being useful to the community.

EDUCATIONAL CONTENT

Proverbs are statements of accumulated wisdom within a given community. They are used to ensure acceptable social behaviour. They therefore point to social skills that are cherished in that community, such as helping those who are weak and/or young or communicating with respect. However, proverbs are rather abstract. Stories, on the other hand, are easier to follow and interpret. The stories collected in this study contain aspects of local geography in terms of climate and economic activities and citizenship. For example, in one story (Kaguru Kamwe), the setting is a natural disaster, such as famine, which occurs from time to time in the central parts of mainland Tanzania. The narrator reminds the listeners (children) of a situation they have experienced in the past and points out especially to younger children what they are likely to find themselves in, unless there is change in the climatic pattern, as they grow older. The second related point in the story is that different parts of the country have different climatic conditions. It is, therefore, possible to survive the situation if supplies can be obtained from areas where the climate is more favourable. However, this is only possible when there is peace with neighbouring communities, good leadership, people work hard, and support and trust one another. Kaguru Kamwe's impairment is used figuratively and metaphorically to highlight family responsibility, special skills and exceptional courage, on the one hand, and the dangers of conflict between communities and limited support and trust on the other. Stories not only carry the content to be learned, but also indicate how this content is to be learned. The subject matter and attitudes towards impairments were learned by means of a series of brief, alternating activities, namely listening, singing, predicting, questioning and discussing. At strategic points during the progress of the storytelling, the narrator asked questions to assess whether his/her audience was following the story. Use of songs in storytelling assists listeners to remember the story. Singing is also enjoyable. In addition, the frequent change of activity ensures that the narrator does not lose the audience. Storytelling also ensures that peer and cross-age support takes place. During discussion as well as when individual children respond to questions, different listeners help to clarify issues so that all listeners are with the narrator most of the time. However, responsibility for learning rests with individual children. They are encouraged to ask questions and this is clearly so when grandparents, and sometimes aunts or uncles, with whom children tend to be freer, are involved. The narrator asks listeners to tell their stories as they know them. This encourages them to learn as many stories as possible so that they are able to contribute. In the process, some children also invent their own stories.

Discussion

Most folklore presents itself in metaphors; that is, one concept is expressed in terms of another. As such, its interpretation needs to recognise the existence of at least two meanings. Reference to impairment often represents a *surface meaning* from which its characteristics, associated limitations and attitudes have been derived. However, the impairment or person with impairment referred to is merely a vehicle for offering advice, instruction or presenting a moral in relation to a specific aspect of everyday life. This second concept represents the *deep meaning* of the folklore. It is evident that the folklore as explored in this study provides data on attitudes and beliefs as well as on the educational content and process as practised in informal settings in Africa. These two areas are presented and briefly discussed below.

Perception and Attitudes in the Folklore

Five major findings on perception and attitudes can be discerned from the folklore data. These were 1. absence of the general category referred to as disability; 2. accuracy of the description of people with specific impairments; 3. belief that impairments were a social reality in everyday life and one source of differentness and diversity in society; 4. unfavourable attitudes towards persons with impairments existed, but were found in only a very small number of proverbs (3 %); and 5. that the human person was valued even when the usefulness of the person with impairment was minimal. Miles (1983: v), in his study of attitudes towards persons with disability in Pakistan, contends that, despite the existence of a mixture of attitudes towards persons with disability in all cultures in time and space, the dominant type of attitudes have progressively changed from "negative, stigmatising and rejecting attitudes, through pity and compassion, towards willingness to accept disabled persons on equal terms". Indeed, this mixture was evident in the folklore analysed in this study. However, in using folklore in the form of old proverbs and stories we are attempting to interpret the past in terms of the present social theorising. Given that knowledge is not static and that social organisation and structures as well as economic and other cultural conditions have changed over time, our interpretations may only represent outsider, rather than insider, views and may, therefore, at best be flawed. However, the parables associated with the proverbs which are being collected should be an important guide to our interpretations. Nevertheless, it is worth pointing out that the language used to describe specific impairments has been the subject of criticism among some people with impairments, especially within impairment-based organisations. For example, the Tanzania League of the Blind are opposed to the use of the word *kipofu* (singular) or *vipofu* (plural), the Kiswahili equivalent of the term *blind*. They claim that the word is a product of an historical elision from two words, *kipo* (it is there) and *kifu* (a dead thing). Their preferred term is *asiyeona* (a person who does not see) or *wasioona* (its plural form). In this respect, it is possible to surmise that historically attitudes towards blind people were not favourable.

Use of Folklore in Schools for Attitude Change

The obvious progression of attitudes thus noted from negative in the past to more positive at present may be a pointer to the need to use some aspects of the folklore in our schools to teach responsibility as well to facilitate inclusion of people with impairments. It is sad to find children in some African nursery and primary schools singing songs and narrating stories from Europe. Considering that we are fast losing the oral tradition, it is absurd that we are not making adequate use of this rich heritage and putting this precious folklore in writing for future generations. Schools could also benefit from the use of local knowledge systems in the current move towards inclusive education. The community focus on impairments rather than the broader disability category and the pervasive notion of impairment as a social leveller connote diversity in society and differences in individual learning needs which teachers should respond to in ways that stretch each learner beyond their current competency level.

Teaching and Learning

In addition to the content of the folklore, which is informative in terms of perceptions, beliefs and attitudes towards impairment, there were specific knowledge areas which were taught and reflected through proverbs, songs, stories and riddles. In the *Kaguru Kamwe* story referred to above, social studies were part of the teaching agenda, although not labelled as such. In the proverbs, stories and songs, such subject areas as family life, education, ecology, uses of plants and animals, appropriate technology, counselling skills, communication skills and legal rights were included. The subject areas addressed were relevant to the local conditions. Indeed, observers consider this aspect as one of the strengths of indigenous forms of education in Africa (Ociiti 1994; Bray et al. 1986). Those concerned with the current state of school curricula have lamented that areas of particular relevance to learners' prior knowledge tend to be omitted or relegated to the background (Salia-Bao 1989). No wonder many children experience difficulties in school learning and find themselves pushed out of the school system. There is need, therefore, to consider the content of the curriculum when planning for inclusion of children with special needs due to impairments.

Perhaps more important to consider than the curriculum or knowledge areas, is the process by which this content was communicated, shared and/or advanced. This consideration has implications for classroom practice in Tanzania. The proverbs, stories and riddles told by the fireside did not involve one-to-one individualised teaching. From my personal experience, the process was enjoyably interactive and the older people encouraged the participation of all children, whatever the level of learning needs. Whereas active learning is reflected in storytelling, some classrooms continue to use the banking method (Freire 1972) introduced when schooling was first established (see e.g. Stambach 1993 for an ethnographic description of some classrooms in Tanzania). It seems to me, therefore, that there is a mismatch between the active learning in the inclusive practice of informal education and classroom experiences. Can all classroom teachers in Tanzania learn to include as facilitators do in informal education? Unfortunately, we have learned to ignore, or see as inferior, what is at our doorstep in favour of what comes from those we consider the powerful and successful.

Limitation of Studies Based on Folklore

Undoubtedly, as stated earlier, the interpretation of folklore is attended by a number of difficulties. First, the folklore may be based on superstition (Possi 1996) and fear of the unknown. As such the messages passed on from one generation to another may be uninformed by current changes in society. However, much of the folklore also changes with time. For instance, the poems and songs of the 1950s are different from those of the 1990s. Second, the issue of translation of folklore from one language to another may distort the original meaning, especially of proverbs. Third, since metaphors are used, it is very possible to miss out much disability-related folklore, especially in the areas of care, education and employment. For instance, Serpell (1993), in discussing education in Zambia, has referred to a number of proverbs which are directly relevant to *disability*, but may be missed when interviews on disability-related folklore are asked for.

CONCLUSION

The characteristics of major impairments are clearly represented in the collection of folklore from Tanzania. These include visual, hearing, physical, intellectual and behavioural impairments and difficulties. Closely linked to the characteristics are the limitations imposed by each impairment. There are very few instances in which negative attitudes were identified. Public attitudes reflect fairness and equal opportunities for all community members, including those with impairments. It seems plausible from the data in this study that community attitudes follow patterns in any other country in the world, namely a mixture of positive and negative images and practices (Miles 1983), save for differences in type, degree and what is considered *politically correct* on the international scene. However, folklore data indicate that features of inclusive education meant to meet the needs of all learners through appropriate school and teacher responses are in-built into informal and non-formal education. Although the demands of the school are different, the functional relevance of the curriculum and teaching/learning processes in the informal/non-formal sector is applicable to an inclusive school. Why has this sector been ignored or relegated to the background? The poor can learn from their past and the rich can learn from the poor!

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BLINDNESS IN SOUTH AND EAST ASIA: USING HISTORY TO INFORM DEVELOPMENT

M. Miles

In recent decades a comfortable set of myths has been constructed about disability and service development in the histories of Asian countries. They tell the story that, *in the old days*, before the pale foreign devils sailed up in their little ships, disabled people were cared for in their families and were integrated and accepted in their communities. Sometimes they were involved in religious functions, or had places as entertainers at the ruler's court. Sometimes they memorised the history of the tribe and told the old stories to the children. Some of them were skilled artists or craftspeople. Then came the ignorant colonialists and narrow-minded missionaries, who brutally snatched the land, tricked the rulers, trampled on the local gods and customs, forced people to wear trousers, and banned the simple pleasures of life, such as sex and liquor. Disabled people were herded into cold, segregated institutions, where they either died of neglect or were forcibly converted to foreign devilry. Only now, after long years of miserable exclusion, are disabled people beginning to be rescued by lovely, cool, refreshing Community Based Rehabilitation and Inclusive Education.

Like all well-constructed myths, there are some truths hidden in this set. And like most myths, this set provides simple and misleading answers to highly complex questions. One alternative is to examine some historical sources, to see whether a more accurate, less sentimental picture can be constructed. Ideally, this should be done by blind Asian researchers. However, the sources presented here required much searching of obscure books, journals and archival materials in English, which remain doubly inaccessible to blind Asians. The first stage in retrieving blind Asian history is simply to show that materials do exist and that modern myths can be challenged by stories that are both more accurate and more interesting. This may open doors for subsequent search and interpretation by people with a more personal understanding of blindness in Asia. The self-empowerment of blind Asians, by which they may take an increasing part in developing their own futures, is more likely when they stand on solid historical-cultural ground, knowing how blind Asians lived in the past and how they interacted with their societies, rather than merely swallowing the conventional myths.

Two different sorts of evidence will briefly be sketched here:

1. Blindness in Bengali folk ballads, suggesting the rural social background and attitudes during the past millennium.
2. Missionary journals showing blind people being taught reading and handicrafts from the 1830s onward in South and East Asian cities, in ordinary schools.

Some discussion will follow about why the latter evidence was neglected for over a century, together with some implications for current developments.

BLINDNESS IN OLD BENGAL

In the early 1920s, a penniless young scholar in chronic ill-health, Chandra Kumar De, criss-crossed the villages of Eastern Mymensing seeking to learn old Bengali folksongs from individual singers – who were mostly reluctant to disclose them to a stranger. Those that could be recovered were translated and published by Dinesh Chandra Sen as the authentic ancient voice of the Bengali rural people, "unadulterated metal of a high quality recovered from the purely Bengali mine".[1] Sen was delighted by the simple rusticity of the folk verses, a little known part of a vernacular literature that was then barely emerging from the contempt in which it had long been held by his own countrymen. The ballads in some cases date back as far as the 10th century CE.

Blindness, usually in male characters, appears in these ballads much more often than other disabilities. This might be because blindness was more prevalent than other disabilities, or was more prominent as a *personal tragedy*, i.e. perceived to render people helpless while not killing them. In each national census 1881–1931, blindness accounted for over 50 percent of disabilities recorded; however, most of those counted were elderly blind people, whereas those in the ballads (originating in earlier centuries) are young or middle-aged. East Bengal, with a damper climate, had less blindness than the Punjab, where the hot, dusty ambience promoted eye disease. Nutritional deficiencies may have played a part in blindness noticed by the balladeers, who record frequent famines and near-starvation levels of subsistence.[2] Perhaps blind singers and musicians laid more emphasis on the disability they knew personally. At least one ballad in Sen's collection was obtained from "an old blind Fakir who begged alms from door to door and earned his living by singing", while authorship of another was claimed by a blind poet, Faziu Fakir.[3] In the latter, the sole mention of blindness compares a son to the traditional guide stick: "He was the sole delight of her unfortunate life and was like the prop of a blind person – her only stay". Another ballad gave an example of happiness as when "a blind man who lost his stick suddenly gets it back while searching it with his hands". Familiarity with the spectacle of blind men deploying sticks for guidance is suggested by the contrasting portrayal of a Raja who gives away his eyes to a blind beggar, so becoming blind himself. Lacking stick experience, he tries to find his way "by feeling things by stretching his hands on all sides".[4] In the ballad of the bloody Nizam Dacoit, a holy fakir disguises himself as an old man, bent with age, tottering along with an *iron* stick in hand. Then Nizam, a criminal turned penitent, uses the stick to smash the skull of a registered sex pest, Jabbar, who is about to exercise his "beastly propensities" upon the corpse of a maiden who had expired after his earlier attentions.[5]

No mention occurs of the *small boy* or other companion, who traditionally leads blind men in some Asian historical tales; nor are medical or surgical solutions hinted at. A specimen of *The Physician* is nicely parodied in one ballad, with his body "polished by constantly rubbing oil over it", his flat nose, trimmed whiskers, and pigeon-like mannerisms – apparently drawn from life. He prescribes with great precision and confidence, then takes his large fee and departs "right glad, and smiling". The patient dies that night. Another ballad depicts a skilled forest healer and his apprentice – the latter outshines his master, who grows jealous and takes revenge. The mass of the populace had no access to any more skilled or organised medical facility.[6] Besides, for the balladeers' purposes, there would not have been much drama in depicting the tragedy of blindness falling upon someone, if an ophthalmological solution were readily available.

The ballad of Kanchanmala, *The bride of a blind baby*, is thought to be among the oldest. The blind baby appears, carried by its widower father, a Brahmin beggar keen to be relieved of the burden. Kanchanmala's father promptly averts an evil omen by marrying Kanchanmala, aged nine, to the baby. A heart-rending tale ensues. Kanchanmala, bewailing her misfortune, heads off into the forest with her new husband or toy boy. The babe's eyes (and other problems) are cured by a sage, but later he is abducted. Kanchan wanders the earth seeking him. Eventually she finds him now equipped with a new wife. Kanchan gets herself hired as their servant, and re-establishes herself in her husband's affections. The second wife, Princess Kunjalata, learns the whole story and has Kanchan expelled. After further vicissitudes she meets her husband again, now a beggar with eyes blinded by continuous weeping. She resorts again to the sage, who agrees to fix the blindness, only on the rather perverse condition that Kanchan return her husband to Wife No. 2, doing so with perfect tranquillity of mind. Kanchan rises to the challenge; then wanders off into a sombre sunset. The singer falls silent, leaving the audience sobbing. Here, blindness (in a helpless male) provides an opportunity for female devotion, self-sacrifice and nobility of soul. Kanchanmala shows resourcefulness in coping with the twists of fate; her husband is merely two-dimensional, whether blind or sighted. The problem that the *natural* caretaker was the baby's mother was avoided by removing her at the outset. As a woman deemed responsible for producing a blind baby, she would already be considered *guilty*, thus not a good vehicle for nobility of soul. Kanchanmala, on first seeing the baby, asks "Did its cruel mother leave it on the wayside?", evidently not an uncommon solution.[7]

More assertive is the hero of the Ballad of the Blind Lover, part of which is told from the handsome blind youth's viewpoint (or at least, the viewpoint of a sighted person guessing the thoughts of one congenitally blind ...). It opens with him begging alms door to door, proclaiming his isolation and desperation, while his haunting flute beguiles the minds of householder and princess alike. The king, enchanted (but perhaps lacking in foresight or Freudian insight), engages the young man to give his daughter flute lessons. The blind youth describes his life as a fluting beggar:

> I have no name, princess. They call me a *mad fellow* and mock me. There are some who take delight in throwing dust at my person and annoying me in other ways, while there are kind men who receive me well. Some serve me with refuse food and think that the mad man would be glad at such an act of charity.[8]

Of course, the princess falls madly in love with him. True, in her first response to the magic flute she displayed some glimmering of intelligence: after planning to give the blind beggar a lucky dip in her father's treasury, she paused to think *"First let us know what it is that he seeks"* – a question still frequently omitted from the planning processes of modern disability services. That exhausts the princess's stock of perspicacity, so the tale moves inexorably to its soggy conclusion.

Apart from poetry, music and begging (often in combination), the only other occupation for blind men mentioned in the ballads is that of one boatman – but he was blind in one eye only, and doubtless one-eyed people kept many jobs. Among the tribal Garrows, living in the northern part of the area in which the ballads were collected, there was reportedly "in most villages, a lame or blind person, incapacitated from other work, who invokes the deities, and offers sacrifices for the recovery of sick persons".[9] This pragmatic, if slightly cynical, matching of capacity with occupation may suggest something of the calculating rustic approach to religion, rather than any special consideration for including disabled people in the life of the community. The deities must be given their due, for what it's worth – but there is no point in wasting an able-bodied man on the job, when a blind or lame one can just as well chant the prayers, sprinkle the blood, or whatever the custom may be.

The ballads suggest that in East Bengal, as elsewhere in South Asia, blindness was a familiar *personal tragedy*, and one that could be savoured by a public audience. The image of the blind person (usually male) was compounded of helplessness and pitiful begging, with the appeal sometimes enhanced by skills of music and poetry. Mobility was possible with a beloved stick for guidance. Blindness constituted an opportunity (even a demand) for female self-sacrifice in caring for the blind child, husband or sometimes elderly relative. Occasionally it might be relieved by miraculous healing, but usually it was a hopeless, lifelong affliction.

WIDER PORTRAYALS OF BLINDNESS

Of course, blindness and blind people appear much more widely in the literature of South and East Asian antiquity, but seldom from a humble, rural perspective. Some legal and charitable provisions existed, and blind characters played a role in epic stories. Guilds of blind musicians and fortune tellers date far back in China's history.[10] The central plot of the great Indian compendium of knowledge, Mahabharata, turns on the prohibition against blind Dhritarashtra becoming king, and contains many other references to visual impairment. India's ancient law-code of Kautilya banned discriminatory language, including ironic terms for blindness.[11] Institutional asylums for blind and other disabled people have a history of over 2,000 years in Sri Lanka, and were known in India and China for many centuries, often in connection with a religious order. Nevertheless, most blind people in both countries, especially women, presumably lived quite constricted lives in their family home. A few occupations such as singing and massage have traditionally been practised, but the most common public image of the blind man has been as a beggar; or the blind woman, especially in China, as a prostitute.[12] To these long and varied histories of social responses to blind people, Europeans brought one simple but significant innovation, characteristic of the Protestant cultural heritage: they had methods for teaching blind people to read, with the aim that they should have the Christian scriptures at their fingertips.

BLIND LEARNERS AND TEACHERS

Official dates for the start of formal teaching of blind people have been 1874 in China, and 1886 in India; but in fact, there was well documented educational work from the 1830s onward, in both countries. Two of the key teachers were blind women, one Chinese and one Indian.[13]

China: In 1837, missionary teacher Mary Gutzlaff began adopting young blind Chinese girls in her boarding school at Macau, and teaching them. Though she lacked specialist training, Mrs Gutzlaff can be regarded as the first pioneer teacher of blind girls in China, with the additional merit that this education was conducted in an *inclusive* setting. Four of her blind pupils were sent on to London for education, where three of them died.[14] Only one, named *Agnes Gutzlaff*, survived to complete her education. She returned in 1856, going to Ningpo, South China, then to Shanghai, where she taught blind children and adults. Agnes was the first trained person in the history of China to teach blind people to read, as well as supervising handicraft activities. She herself had learnt to read first the Lucas system, embossed script based on shorthand notation, then Moon's embossed script. The latter was invented in England by William Moon after he became blind. Moon offered to send his teachers to any ordinary school to teach his embossed script to sighted children, who would then teach blind adults or children living nearby. The offer was taken up in many places. Moon script required only a few days to learn, being based on the shapes of English letters or whatever local alphabet was used. From about 1850 onwards, missionaries in many countries made use of Moon script (Braille was not widely known and used until later).

Agnes Gutzlaff was a musician, and also supported herself by teaching English. She bequeathed her savings to found the Gutzlaff Hospital, a small institution which ran for several years until it was amalgamated with St. Luke's Hospital, Shanghai.[15] Meanwhile, in the late 1840s, a class of blind adults had received formal instruction from Thomas McClatchie, an Anglican priest at Shanghai. On the 4th November 1856, another clergyman, Edward Syle, opened the first workshop at Shanghai, for elderly blind people, after various efforts to find useful occupations for blind members of his congregation. The lives of some blind people, and the thoughts of the pioneers, appear in their letters and contemporary journal papers.[16]

India: William Cruickshanks, who went blind during his boyhood in an orphanage at Madras, persevered with his education integrated with sighted boys. He succeeded in becoming a teacher, then from 1838 to 1876 was headmaster of several ordinary schools in South India.[17] Teachers at the Bengal Military Orphan Asylum, Calcutta, were concerned about some blind children in the orphanage school, and asked for help from the London Society for Teaching the Blind to Read. With materials supplied from London, the orphanage school had adopted the Lucas reading system by 1840.[18] This was overtaken by books in Moon script in several Indian languages from 1853 onwards. Missionary women such as Jane Leupolt, Emma Fuller, Mary Däuble, Elizabeth Alexander and Maria Erhardt used Moon books to teach several hundred blind children in integrated classes at Benares, Agra and in the Punjab in the 1860s and 1870s, as evidenced by Government records and missionary journal reports.[19] The first regular teacher at an *industrial school* for blind people was Miss Asho, a blind young woman who had been educated in an ordinary girls' school at Lahore. Asho read first Moon, then Braille, and was competent at various handicrafts. When Sarah Hewlett and Annie Sharp opened a school for blind women at Amritsar, they recruited Asho as their first teacher, and regarded the school as having started properly upon her arrival.[20]

Moon script was much easier to learn than Braille, but much costlier to print, taking up far more space. Both were used in South Asia for several decades. Finally *high tech* Braille, which needed a competent professional to teach its use but also had bigger potential through the growing availability of Brailled books, eclipsed *low tech* Moon script, which most people could learn quickly and then teach to someone else but which had limitations in the cost and availability of materials (Moon script slowly declined and is now unknown in Asia, though it has had a revival in Britain among people who cannot use Braille, and its printing is now less costly). The cost factor was important in India, as the early work with blind children was seldom supported by foreign mission funds – missionaries had to find their own funding for it – and very little government funding was available. As Braille literature began to be more widely available, and at lower cost, it began to be seen as more attractive for educating larger numbers of blind people, even though it added to the *professionalisation* of special education, and the development of segregated schools. If Braille was used, then specially trained teachers were needed, and these were in short supply. So when they were available, it made economic sense for them to work in specialised schools where their skills could be applied to the maximum number of students. These and many other factors were seldom if ever controlled or planned in a strategic way. In each place, the few people who were developing services used whatever meagre resources, techniques and materials they could find, to get the best results they could with their students, but also sometimes to meet other agendas and motivations of which we get occasional glimpses.

MISSING FACTORS

Later accounts of work by and with blind people in South and East Asia have very largely omitted the earlier cultural background, several decades of experiences with *casual integration* in ordinary schools, and the prominent parts played by teachers who were themselves blind. Many of the pioneers, both blind and sighted, were women, labouring under a double social disadvantage. They were using the successful new reading materials of their times, first the Lucas system and then Moon's embossed script, while Braille's dots slowly gained ground elsewhere. The efforts of some active blind Asians to learn whatever they could, and then to teach others, were appreciated and recorded by their sighted mentors at the time; but these efforts mostly disappeared from accounts given by later chroniclers, or were given a very subordinate place, influenced perhaps by an expectation that good works *must have been* done by sighted missionary philanthropists to *helpless* blind natives. Yet this cannot be the whole explanation, as some earlier sighted pioneers also suffered the fate of being wiped out of history.

The sighted pioneers acted in real, grass-roots situations, and saw the practical benefits and drawbacks that resulted. After them came administrators and managers, who institutionalised the pioneers' work and who were often one step removed from grass-roots and front-line. After another generation or two, came the spin-doctors, dependent on secondary sources, selecting certain historical points for special emphasis while downgrading others. In mission historiography from 1900 to 1950, the missionaries of the 1880s are recognised for founding enduring institutions. Their actual dependence on Asian colleagues, some sighted, some blind, tends to be ignored. Records of the work of earlier missionaries and blind colleagues, who used innovative methods in integrated situations, have been sitting in journals and archives all along, but were not perceived as a significant contribution. Even now, when institutions have become unfashionable and Integration (now updated as Inclusion) is the buzz-word, one may expect several decades to pass before the 1830–1880 pioneers of integrated education subvert the conventional mythology.

Implications for Development

The main *lesson from history* (a highly unfashionable concept) is that we can expect to be involved in just as big a muddle as earlier generations, but it will not be quite the same muddle, so we should not merely imitate those who appear to have been winners in earlier times. Personal drives among professionals and development agents, such as power-seeking, ambition and curiosity, and the domination of disabled people by able-bodied, of rural people by urban, of women by men, of children by adults, of clients by professionals, and of the poor by the wealthy, all remain practically unchanged. The drive for social justice and the wish to offer disabled people a chance to acquire some education also seem to persist, though these motivations are doubted by certain sociologists (whose own motivations are sometimes hard to discern). Changes are observable in the distribution and circulation of knowledge, and the elaboration of technique; but rural areas and city slums, where most of the world still lives, still suffer apparently permanent information famines while the wealthy parts suffer information overload. Disability service planning has long been damaged by furious battles over method and technique – e.g. the oral/manual controversy in deaf education, battles over embossed scripts for blind readers, behaviourist approaches for people with learning difficulties. The vague, often sentimentalised, Princess-Diana-like desire to *do something for* disabled children easily gets co-opted onto an ideological bandwagon, resulting in wonderful schemes hatched in Geneva, endorsed in New York, funded in Stockholm, but never at any point passing across the desk of anyone with practical field experience of disability service development in economically weaker countries.

South and East Asia between them have over 50 percent of the world's blind and low-vision population, mostly living in rural areas where no formal specialised education or training is available. The informal service provided by millions of family members is still seldom informed by modern knowledge and technique. Some hundreds of urban special schools, units and training centres now exist, with access to modern educational and vocational methods, and with some teachers who have been exposed to recent European approaches.[21] Yet these formal services, worthy as they are, still reach only a small proportion of those who might benefit from them. Furthermore, they tend to lack roots within the cultural and conceptual heritages of these vast populations. There is little, if any, feeling of a dynamic continuity with the past, nor any awareness that some blind Chinese and Indians themselves took up the challenges 150 years earlier and contributed to service development, both educational and vocational. That is a gulf needing to be bridged. In the long run, if services are to become culturally and conceptually more appropriate and effective, blind Asians must gather confidence in themselves and make significant and well-informed inputs to planning, implementation and monitoring of services. To know where they are now and where they wish to go, they should know where they have come from.

NOTES

1 Sen (1923–32) I (i) xiii–xxii.
2 Sen, I (i) 170; II (i) 41–45; 223–225; et passim. See also Das Gupta (1935), 275–277.
3 Sen, II (i) 379, 391, 424.
4 Sen, II (i) 403; IV (i) 50; see also Sen, II (i) 200, 228. Similarly, "You are the lamp of my house, precious to me as the prop is to the blind." II (i) 450. These metaphors reflect actual observation, in contrast to the other stock images, i.e. the supposed longing of the blind man to regain his sight, or his imagined joy on receiving it, e.g. II (i) 251, 340; IV (i) 105, 389–390.
5 Sen, IV (i) 394; II (i) 286, 292–293.
6 Sen, II (i) 234–235; IV (i) 410–424. Indigenous eye surgery was certainly practised in Bengal. Some European observers admired it, e.g. Breton (1826).

7 Sen, II (i) 79–116. Sen refers to infanticide following adverse astrological predictions: I (i) 250; II (i) 388 footnote. The father, being a Brahmin ascetic, displays his moral worth first by carrying the blind baby around for several months (instead of dumping it in a ditch), then finding it a good home. Thus disencumbered, he can "start for the holy shrines of Gaya and Benares", II (i), 89–90.

8 Sen, IV (i) 211–237, on p. 223. A similar description from an old, blind Brahmin beggar appears in another ballad, see IV (i), 389–390.

9 Note by A. Watson, in: White (1832), 139.

10 For China, see e.g. references to blind people in Legge (1879); Waley (1992); Mackenzie and Flowers (1947) 25–35; Burgess (1928) 66–75, 117–118, 124, 131, 137, 159–160, 164, 193, 201–203; Fairbank (1994) 274 and Plate 15; Milne (1857) 49–55; Tsu (1917).

11 For India, see e.g. Ganguli (1883–1896) Adi Parva, Sect. CIV, CIX, CX, CXLIII, CCXXV; Vana Parva, Sect. XLIX; Doniger and Smith (1991) 60, 62, 220; Kautilya's Arthasastra (1961) 236; Roy (1960); Lehmann (1982).

12 Efforts to suppress begging and to find paid employment for blind Chinese people were reported from the 1570s by Mendoza (1588) 66–68. For the blind woman, however, "when she commeth unto age, she doth use the office of women of love (i.e. works as a prostitute), of which sorte there are a great number in publike places" (68). See also Hoe (1991) 173–176; MacGillivray (1914) 589; Ching (1980) 19–21, 47, 50, 274–275. Blindness became an advantage in a prostitute presumably because the client's own identity and defects were thereby spared any scrutiny. There was only a defenceless body for temporary hire.

13 An extended study by Miles (1998) appears on ERIC ED414701 and at the History of Education Website.

14 E.M.I. (1842; this concerns the blind girl Mary Gutzlaff, not Mrs Mary Gutzlaff); The Blind and their Books (1859); The History of Lucy Gutzlaff (1844); Archives of the Royal London Society for the Blind, Female Register.

15 Female Missionary Intelligencer (1855) II: 110–119; (1858) new series I: 110–111, 125; (1859) II: 64, 96. London Society for Teaching the Blind to Read, 20th Report (1858) 8; 21st Rpt (1859) 7; 40th Rpt (1878) 15–16. CIM/OMF Archives, CIM/JHT 74–81, Bundle 3214, letter from Dr Moon. Society for Supplying Home Teachers, 3rd Rpt (1859) 20; 5th Rpt (1861) 13–14. Church Missionary Record (Nov. 1861) 348. North China Herald (18 Apr. 1874) 331–334. China, Shanghai: Customs Gazette, Medical Reports, (1873 onwards), No. 4: 100, 103; No. 7: 43-44; No. 8: 64–65; No. 11: 57–58; No. 12: 10–13; No. 14: 45–47; No. 15: 6–9; No. 17: 18, 28–31; No. 18: 82; No. 19: 19, 21–24; No. 21: 83–84, 92; No. 26: 18–19.

16 Chinese Recorder (1868) I: 138–140; (1877) VIII: 308–310; (1890) XXII: 23–25. Spirit of Missions (1849) XIV: 343–346; (1850) XV: 185-187; (1851) XVI: 73–82; (1852) XVII: 201–205, 304–307, 445–451; (1857) XXII: 26–37, 275–279, 385–390; (1858) XXIII: 194–197, 335–339, 483–485; (1869)

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17 Church Missionary Gleaner (1879) 6: 65 & 76–77.

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SOME CULTURAL REPRESENTATIONS OF DISABILITY IN JORDAN: CONCEPTS AND BELIEFS

Majid Turmusani

DISABILITY IN JORDAN: HISTORICAL DEVELOPMENT

The development of Jordanian society has always been associated with the issue of refugees from other countries, especially Palestinians who fled their home to Jordan (e.g. in the West Bank conflict and the Gulf War). These events culminated in Jordan becoming the focus of international attention as well as international aid in an attempt to accommodate these refugees, some of whom had impairments and required special provisions (Turmusani 1998). The first response to meeting the needs of disabled people in Jordan was foreign NGOs in the sixties providing care for severely deaf and mentally retarded people. In the 1970s government and voluntary organisations got involved in providing care for mentally retarded people. The International Year of Disabled Persons (IYDP), 1981, has also played a crucial role in stimulating the awareness of all sectors of disability issues, and is considered to have been a turning point in the state's agenda with regard to disabled people in Jordan.

However, it can be argued that Jordan has taken steps to provide disabled people with the appropriate services (i.e. education, rehabilitation, etc.), in an attempt not only to make them contributing elements to their society as indicated in (IYDP) 1981, but also to meet religious obligations of providing equal opportunities to people regardless of their mental, physical and/or economic condition. The philosophy of equal rights is illustrated by a number of verses from the *Holy Qur'an* as follows:

> O mankind! we created you from a single (pair) of a male and a female, and made you into nations and tribes, that ye may know each other (not that ye may despise each other). Verily the most honoured of you in the sight of Allah is (he who is) the most righteous of you. And Allah has full knowledge and is well-acquainted (with all things). (Ali 1994)

As it can be seen from this statement that all people are the same as human beings, and have equal rights and dignity, regardless of their age, sex, origin, colour, or health status, the only scale is the degree of faith. Having said that, it is important to note that while some passages from *Qur'an* such as the previous one have contributed to a relatively favourable image of disabled people, others have contributed to more negative attitudes towards them and been used to justify their exclusion, as will be discussed shortly.

ATTITUDES, CONCEPTS AND BELIEFS REGARDING DISABILITY IN JORDAN

The literature reviewed together with the empirical findings of this research concerning attitudes and beliefs about disability, showed that disabled people were viewed negatively by the general public in Jordan, especially with regard to their ability to make an economic contribution to society. Evidence from the empirical research that this paper is based upon demonstrates the compelling need for a change in attitudes towards disabled people and their abilities among the general public and particularly among employers, teachers, and even among disabled people themselves as regards the perception of their rights and needs (Turmusani 1999). Khatib (1989) argues that until recently, the Arab societies, including Jordan, treated the category of disabled people as a negligible quantity, and community systems directly or indirectly reinforced this tendency, treating disabled people as though it was the end of the road for them. Any investment in their favour was considered to be a burden on the state. Disability, in Arab culture, has traditionally been seen as something shameful, an ordeal to be endured by the family that has in its midst a disabled person. Thus, Arab families have often failed to admit that they include a disabled person, for fear that this would be considered a disgrace which lowered the family's standing among its neighbours (Khatib 1989). Feelings of guilt and pity may exist and some parents consequently keep their disabled children hidden away, which denies them the opportunities to acquire the available services that are necessary for their integration. Families with disabled daughters were particularly prone to deny having a disabled person in them, for a fear other families would be discouraged from considering marital alliances with them (Coleridge 1993). The attitudes of the family towards a disabled member tend to be largely influenced by the attitudes of the larger community.

The dominant Islamic faith in Jordanian society and its teaching attributes anything that occurs, and all that exists in the world, to the will of God. Therefore, society tends to perceive disability as an act of God, testing the belief of individuals to determine who is able to accept and tolerate their fate with gratitude and patience and those who are unable to bear such tragedy (Khan 1979: VII: 374–377). Disability is looked upon as a test or as God's will and it is up to the person not to show their distress or bad feeling towards it. This is due to the fact that one fundamental element of Islamic religion is the belief in *Quadah* and *Quder* (belief in God's absolute decree and faith in the concept of predestination, both for good and evil). Therefore, the stronger the faith, the more tolerant a person becomes. This perception of disability as a test of the faith and as God's will shapes attitudes towards disabled people to some degree in Jordan. This notion that disability is the will of Allah and that it shouldn't be changed except in certain circumstances has however resulted in serious hindrance to the use of medical advances to cure some impairments (see Miles 1995).

The practice of amputations of the hands of those commit the crime of theft (in Islamic law) until recently not only deliberately added to the number of disabled people, but also strengthened the stigma associated with physical disability (DAA/UNESCO, 1995). The stigma of amputation has moreover had an especially negative, knock-on effect by making amputation surgery particularly distasteful and therefore, may have discouraged some people from seeking medical surgery for certain diseases.

MISCONCEPTIONS AND REALITIES ASSOCIATED WITH DISABILITY IN ISLAM: CONCEPTS AND BELIEFS

Although research regarding disability in some cultures of the South shows that disabled people are not discriminated against and that some of them are somehow integrated into the socio-economic life of their societies (Ingstad 1995; Albrecht 1992), a closer look at their situation reveals a different reality. In Jordan, for example, discrimination against disabled people has existed and such discrimination is largely founded on Islamic teachings from *Qur'an* and *Hadith*. For example, discrimination against disabled people in Islam can be seen in a number of statements from the *Qur'an* and the *Hadith* which refer to people with impairments in a negative way. These include verses which associate sins with the stigma of impairment (Hilali and Khan 1996; Ali 1994; Al Baqra, verse 282; An-

Nahl, verses 75–76; Al-Fatr verses 19–22; Yasin verses 65–67; Bani Isra'l verse 97; Khan 1979: 1033); and which dictate amputation as the punishment for outlaws (Ali 1994; Al Mumtahinah verse 12; Al Ma'dih verse 41). Reference is also made to women in the *Qur'an* which suggests an intellectual deficiency which in turn compounds the negative view of women who are also disabled (Khan 1979, VII 21–22, 80–81, 95–98).

It can be argued that in Jordan, the general public has employed until recently a definition of disability based on the concept of *visibility of impairment*. For example those with mild impairments and hidden impairments were not viewed as disabled, and even those with moderate mental retardation were referred to as patients and not disabled, as were those with some deficiency (Turmusani 1999). This can lead to both positive and negative consequences in the sense that disabled people with mild and hidden impairments will not be discriminated against by the general public as they are not perceived as disabled, but on the other hand they might not be entitled to services because they are not defined as disabled. For example only cases of visible impairment were considered as disability in the only Jordanian national survey conducted, by the Queen Alia Fund (QAF) in 1979, as until very recently some impairments like speech deficits and learning difficulties were not defined as disabilities (QAF 1979). It is believed that this survey has served to keep the disability issue low on the public agenda. In fact, the political implication of such a survey has been obvious for the national agenda concerning disability issues in the sense that the *disabled population* was presented as limited in number and this delayed the inclusion of disability issues in the national agenda as a priority.

There was no official definition of disability in Jordan until recently. Both the definition employed by professionals and that mentioned in the new law are based on the WHO. The official legal definition basically defines a person with disability as:

> any person with a permanent, partial or total impairment in any of his senses or physical, psychological or mental abilities to the extent that the ability to learn, to be rehabilitated or to work is limited in a way which renders him/her incapable of fulfilling his/her normal daily requirements in circumstances similar to those of able bodied persons. (Law 12/1993)

It should be noted, however, that underlying this definition is a medical view of disability, the obvious example being the association of the notion of welfarism with the title of disability legislation. This association of welfarism and disability (i.e. the Law for the Welfare of Disabled Persons) rather than a rights perspective implies the incorporation of a medical view that disabled people are dependent on others and may suggest that they need to be looked after by professionals. This is shown in that in the Arabic language used in the legislation, the word welfare literally means care provided by professionals who are in full control over the business of care. Welfarism in disability issues, if implemented from a rights perspective, is essential in meeting disabled people's needs and helps in their emancipation (see Turmusani 1998).

In discussing the way definitions and concepts of disability are constructed in Jordan it's becoming necessary to address how the Arabic language portrays the image of those with impairments. Arabic language and literature places great emphasis on spoken language and verbal communication as an important art that people should master in their everyday life. The coherence of language, along with its clarity, are two aspects which qualify a person for involvement in public life. Therefore, we can see from the vantage point of history that some of those blind people who have mastered the skills of spoken language, especially reciting *Qur'an,* have managed to reach positions of some power in their societies. The Islamic religion has emphasised the importance of the Arabic language by referring to the holy book as a linguistic miracle. It can be argued that the Arabic language has been to a significant extent used as a linguistic tool to influence the perception towards those with impairments and discriminate against them. This can be seen by the large number of words, terms and proverbs used in Arabic to describe those with different impairments in a negative sense. It should be noted however, that despite the fact that there is nothing wrong with those terms, the problem lies in the cultural and political meaning attached to particular terms and the stigma inferred from these terms, which leads to experiences of discrimination. At present, continuous efforts are being made to change attitudes towards disabled people by changing the sense of the term used from a negative to a positive, especially terms used to describe mentally retarded people. Different terms have consequently been introduced into the literature, such as people with individual needs, people with special needs, etc. However, terms describing the physically impaired, deaf and blind remain the same and those for dyslexia, speech deficits and those with mild impairments remained largely unchanged.

When asked about their needs, those disabled people who were interviewed within the course of this study identified a positive change in attitudes of family, friends and employers as one of their major needs. Many of them placed this need among their first five priorities, which included the need for income, welfare benefits, access and mobility.[1]

However, those interviewed have complained of certain negative attitudes towards them and their abilities, which are illustrated by cultural proverbs. Blind people repeatedly complained of the *charity attitudes* that the public hold towards them, especially when crossing the street. They also complained of certain negative cultural proverbs used to describe them, e.g. *Elie A'mah Ma Ebtalah:* this means that God has inflicted this punishment and test on the blind person, because she/he deserves the punishment in her/his nature. In fact, in some Qur'anic verses, those with visual, hearing and speech impairments are referred to as those who lack mental capabilities. This is to describe those who do wrong and wicked people in society (Ali 1994: Al Baqra 17–20). In this sense, some of the Islamic teachings such as the previous one may be considered to be a hindrance to disabled people, especially when those who don't see, hear, speak or understand are equated with those who do wrong and are wicked in the society. Referring to those with impairments in such a way may have partly led to disability being associated with wickedness and evil and therefore suggest deviance and stigma.

Deaf people too, were not exempt from these negative proverbs, although they didn't bother very much about them, and only those with mild hearing problems made some mention of these proverbs. One person said that he was annoyed by the proverb that described deaf people as those who don't know what is going on around them, assuming that a lack of hearing means a lack of other sensations (i.e. *Zai El Atrash Fi Alzafeh*). This proverb is used to describe able-bodied people who don't know what is going around them, even if they are at a wedding party and the reference made to deafness for illustration. Physically impaired people were the most expressive group of all who have talked about the cultural representation of them and of other categories of disabilities. They made general reference to the common proverb which says that those with impairments are cruel in nature and deserve what had happened to them (e.g. *Kulu Tho A'aeh Jabar* or *Elie Ebtalah Ma Kafah*), the reference here being when someone with impairment responds positively to their impairments and seeks equal rights for themselves. They also mentioned some specific proverbs about physical impairments, these implying that *crippled* people not only lack ability to move but also that their brains and sexuality are affected. It can be concluded therefore, on the basis of these illustrative proverbs, that they may have greatly influenced the beliefs about causes and explanations of impairments and shaped the negative attitudes of the general public towards disabled people in Jordan.

Therefore, it can be said that in spite of the overall positive reference to disabled people in *Qur'an* and *Hadith,* there have been some instances where disability was referred to in a negative sense and also bluntly in a non-metaphorical way. There are several versus from *Qur'an* which are believed to have compounded negative attitudes and associations as regards people with disabilities. The quotation of these verses is largely drawn from Hilali and Khan 1996 and Ali 1994 in their translation of the *Qur'an* as follows: Surah Al Nahl verse 75–76 refers to disabled people as useless, with no power over anything and as a burden on their superiors, and implies that very often wrong-doing results from their behaviour. Surah Yasin, verse 65–67, refers to disability as a punishment from God for those who do wrong. This had indeed led to the stigma of sin being associated with those with impairments and has had very serious negative implications for disabled people's lives. Mohammed's teachings *Hadith* also reveal several stories where negative attitudes towards disabled people were obvious, e.g. the quotation drawn from Khan 1979 in his translation of Sahih Al Bukhari. Disability is mentioned by the prophet as a result of evil eye (Al Bukhari, 1979, Vol. VII 426). Disability is also mentioned as a defect given by God to those who sin (ibid., VII: 374; 376–377). Mohammed taught his companions to run away from a leper as they would run from a lion (ibid., VII: 409).

Disabled people interviewed were furthermore unhappy with some proverbs that seem accommodating, but which in fact express charitable and paternalistic attitudes. For example, the one which says, Don't laugh at an impaired person, for you might be tested by God just the same as him. In fact, there seems to be Qur'anic reference to such accommodating attitudes as well as some statements, but these still adhere to a paternalistic view. Surah Al Nur, verse 61, indicates that there is no harm if blind, lame or sick persons eat together with other able-bodied people. One key informant made reference to the fact that blind people were until recently able to get some income from reciting *Qur'an,* but as the society moved forward and people became able to listen to *Qur'an* through the media and other means, blind people lost this privilege. Although it is argued that disabled adults in Islamic society may have a more secure situation than in some other societies, this is due to the fact that Islamic traditions pay much attention to providing care for elderly people (Miles 1995). Too much emphasis being placed on providing care for and too much respect being paid to the elderly in Islam, might hinder the personal development of other sections of society such as the youth, who are unlikely to have equal opportunity in life because the elderly still dominate and monopolise positions of responsibility in society. It is also believed that the general focus on the community and its primary interests might also hinder the personal development of individuals.

The position of women in Jordan is better and has been improved in comparison to other countries, but is still different from that of men. Women are still considered in some areas to be *awra*, which means that women's faces and bodies must not be exposed to public view. They are not allowed freedom in choosing a husband, in expressing an opinion or living independently. This attitude however is not imposed only by the Islamic religion, but also by the regional culture and traditions that may date from pre-Islamic times (Saadawi 1997; Turmusani 1998). The situation of disabled women within this context would seem particularly difficult. Disabled women, especially those who are mentally retarded, are seen as an endless burden on their families' shoulders, not only morally, but also financially, since most of them don't marry. For these reasons, it can be said that the attitudes towards disabled women are unfavourable when compared to those towards disabled men. A disabled woman frequently becomes the centre of concern for the whole family, not for her own sake and benefits, but for the protection of the family honour. Although the treatment of disabled people has changed considerably over time as regards providing care and rehabilitation, those who are most neglected are disabled girls in rural areas, especially in Muslim countries (Ingstad 1995). In southern Lebanon for instance, it has been reported that a woman was left to die at her half-destroyed house after an Israeli military offensive on her village. The father told the reporters that he had chosen to save their cow rather than his daughter because it was more useful to them (Habib 1998; Disability Awareness in Action [DAA] 1997).

THE IMPACT OF WESTERN NGOS ON DISABILITY CULTURE IN JORDAN

Although the influence of Islamic views has persisted in Jordan, over time there has been increasing Western influence. The process of British colonisation and, more recently, the intervention of Western charitable organisations, has had an effect on local values and attitudes towards disabled people. For example, traditionally care was provided within the context of the family. Western penetration and in particular the coming of NGOs in the post-colonial era of the 1960s has had a major influence on traditional assumptions. With the influence of Western style of modernisation, society's attitudes relating to the care of disabled people have changed from regarding care as being solely a family responsibility to seeing it as being the responsibility of residential institutions or the state, although the role of the family in providing care continues to be essential. Other Western values have also influenced local beliefs in Jordan, namely those underlying the Western NGOs' methods of work, which include practices related to professional control and the assumed passivity of disabled people, both of which are compatible with the medical model of disability. The voluntarism vs. government sponsorship of services for disabled people is an additional legacy that comes from Western influence on Jordan. The provision of comprehensively funded services for disabled people has encouraged reliance on these NGOs and therefore discouraged the development of formal state operated and funded services (Mallory 1993). This has led to marginalising disabled people in institutions rather than integrating them into society.

As a result officials who are involved in disability issues have believed that disabled people should be collected into one place where they can receive appropriate care. But this policy of institutionalisation has caused the issue of disability to be low on government's list of priorities, and has had serious negative consequences regarding the location of disabled people on the welfare state agenda.

In conclusion, the medical model[2] of disability which underlies Western NGOs' methods of work and UN programmes in Jordan have made important contributions to the care, training and opening up of new opportunities for disabled people (i.e. creating provision and legislation, as well as changing beliefs about causes and explanations of disability in the direction of scientific explanations). These programmes however have to some extent contributed to the perpetuation of the difficulties which disabled people face in Jordan (i.e. the responsibility for care discussed earlier) (Turmusani 1998; 1999). In summary of this section it is argued that the primary need of disabled people in Jordan seems to be one of support for indigenous development by indigenous disabled people and professionals. The input of Western professionals and professionals in general should be offered only on request and as a secondary measure.

CONCLUSION

The medical model of disability that underlies both Western NGOs' method of work and some Islamic teachings has greatly influenced concepts, beliefs and attitudes towards disabled people in Jordan and contributed to informing society's policies and practices regarding disability issues. Research findings show the severe disadvantages with regard to the needs and opportunities of disabled people in Jordan, especially in economic life, as a result of the dominance of this medical view. The concern in this paper had been to bring forward ideas related to the social model of disability, such as emancipation and the need for integration of disabled people into the mainstream of society as well as to remove society's discriminatory barriers. As has been illustrated within the text, their emancipation will ultimately require the changing of negative cultural attitudes towards them. This process may be facilitated by recognising the parallels between the social model and some of the already existing cultural ideas, such as equality, justice and participation.

NOTES

1 The empirical research on which this paper is based investigates the economic position of disabled people in Jordan and assesses how disabled people themselves evaluate their economic needs and priorities, with secondary emphases on the way in which existing legislation is addressing this issue. The overriding concern in this research is to contribute to a change in attitudes towards disability issues, particularly the economic participation of disabled people, from their being viewed at the individual level to that of society. The research was conducted during 1996–1997 to gather qualitative data on the perceived economic needs of disabled people by using a research method called participatory rapid appraisal (PRA). It concerned a target group of 181 disabled people who were interviewed within the course of this research. However, only 95 of them took part in the focus group sessions and gave information regarding their needs and priorities including their needs for a positive change in attitudes towards them. This target group included males and females from both rural and urban settings all of whom had sensory impairments (blind, deaf) or were physically impaired and were attending vocational, sheltered and self employment programmes in the Middle Region of Jordan. Research findings reveal the severe disadvantage experienced by disabled people in the areas of employment, welfare benefits, access and mobility. Although many disabled people viewed the satisfaction of their identified needs as a matter of charity, a substantial number of them rejected

this charitable attitude and called for equal rights and opportunities. They went on to request that they be involved in the process of addressing their needs and meeting them. The research concludes that information and awareness are key elements in changing attitudes towards disabled people and their abilities to make a substantial economic contribution to wider society and that the participatory research paradigm that this study is based upon can play an important role in this process (Turmusani 1999).

2 The medical model of disability which is adopted frequently by institutions can be considered as a refuge for disabled people in times of poverty and unemployment, especially in the absence of a welfare system for non-disabled people. Therefore, in many respects this medical model can be considered politically advantageous for disabled people in Jordan. This is despite the fact that this model has many limitations.

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BIO-MEDICAL VERSUS INDIGENOUS APPROACHES TO DISABILITY

Sophie Kasonde-Ng'andu

INTRODUCTION

A world-view is a way of looking at people, events and situations. lt is a learnt way of interpreting situations or defining reality that is common to members of a given cultural (or subcultural) group. Another way of looking at this is in terms of what Skrtic (1986) refers to as a *a paradigm*. According to this view, a paradigm is the way in which we *unrandomise* our experiences and impose some order on the complexities of our lives. lt is a world view constructed by agreement among a community of people using language as a means of communication (Ballard 1995). A biomedical approach to disability, which is associated the with Western world, is based on a paradigm or world-view which differs considerably from an indigenous perspective. The differences in orientational framework of the two schools of thought have influenced social perception of disability and subsequent organisation of resources and services, as this paper attempts to show.

BIOMEDICAL APPROACH TO DISABILITY

lt is important to acknowledge at the outset the contributions of biomedical and medical sciences in the areas involving an identifiable condition, especially pertaining to mental retardation. These conditions frequently have a biomedical cause that results in structural damage to some degree. However, even in this area the cause of disability is not always clear. Apart from genetic factors, environmental ones and/or an interplay of these can cause structural damage. The medical profession has had a long history of involvement in the field of disability in a number of ways. Quite often the physician is the first professional who is approached on matters of identification, diagnosis and in some cases parent counselling. When the disability is evident at birth, the physician is usually the first professional to come in contact with the child. When the disability is not evident at birth but development is slower than usual, the physician is again frequently the professional consulted.

In most cases if not always, the physician views disability as a physiological problem. Although recent years have seen remarkable changes in the medical field, physicians frequently have not had the background to understand the nonmedical ramifications of disability. This substantially limits the effectiveness with which they can approach the total impact that disability has on a family. While professionals should be regarded as heterogeneous individuals with their particular training from the training philosophy interest in each discipline, they are primarily influenced by the clinical perspective of disability. Professionals have been trained to view disabled children/persons from a clinical perspective as patients and clients. Their professional education and experience tend to stress certain dimensions of the client or patient to the exclusion of other aspects. For example the psychologist learns to *see* a client as a composite of scores on intelligence tests and other measures. Specialising in a part precludes emphasis on the whole.

Although professionals and parents may both be part of the larger cultural system, their worlds of experience are likely to differ greatly. Contrary to the professional assumptions, parents have learnt to see their disabled children as sons and daughters who respond to their love and care. Parents see their children's functioning within a variety of social contexts whereas professionals generally interact with them only within the narrow framework of a classroom, office or clinic. To an outsider, who is neither a parent nor part of the family, the limitations of life with a disabled child or person are likely to be more apparent than the rewards. Because of these differences in experiencing reality between parents and professionals, their perceived priorities and methods of achieving them are naturally likely to be different too.

Once the clinical perspective has been taught as part of the professional school curriculum, it is further developed through in-group interaction. As the saying goes: "birds of a feather flock together", and indeed physicians commonly associate, both formally and informally, with other physicians. Other professionals, similarly, maintain contact with their colleagues. Interaction between individuals with similar perspectives almost always reinforces those perspectives (Darling 1982). The regular staff meetings and in-service sessions held in most facilities that serve disabled children/persons are typically attended by specialists from a variety of fields, whose interests may diverge but as noted above, tend to share the biomedical perspective. Parents are almost never invited to attend such sessions, unless their presence is mandated, as in the case of the Parents Charter (U.K. 1991) and P.L. 94–142 (U.S.A.); and when they attend, they are commonly intimidated and overwhelmed by the professional dominance of the *experts* and say little or nothing. In third-world countries like Zambia, where there is no such legislation to safeguard parents' rights, the professionals are *gate keepers* censoring entry into such forums. It should be pointed out that some professionals are, by chance, parents or siblings of disabled individuals. Interestingly, their points of view tend to be closer to those of other families than to those of their professional colleagues (Darling 1982), implying that one has to live the experience of being in such a situation to really see things through the right lenses. No amount of education and biomedical or clinical experience can produce the feelings that come from parenting or living with a disabled child/person. This, however, does not mean that the world-view gap between professionals and parents cannot be narrowed. In other words, despite this gloomy outlook, there is hope for desirable change given conducive conditions which are spelt out later in this paper.

The underlying value behind the clinical or biomedical perspective, which is worth noting, is that disability is a sickness, personal tragedy and object of charity. *Special* needs may not be met as a right, but only on application for *special* help within a context that privileges some human characteristics over others (Ballad 1995). The key question is who determines the world-view that feeds into the various service organisational arrangements. If a paradigm or world-view is made by a relatively small set of people, such as professional educators, physicians and psychologists, it may suit those powerful enough to use it to organise their world, but it may be harmful to others whose experiences are then excluded. Another assumption based on the clinical approach that follows from the foregoing, is that disability is seen as an individual's problem, whereby social relations and society at large have no role to play. This has allowed communities to disclaim responsibility for some individuals and has helped industrial economies to manage people who are less productive (Branson/Miller 1989). Separate or exclusive provision of services including education, health and social welfare, has emerged from a knowledge base heavily coated with such assumptions and biases. One must realise that every professional who deals with disabled persons is armed not only with the relevant professional texts, but with an embedded set of values, experiences and assumptions, some of which adversely impact on and discriminate against persons with disability. To the extent that professionals labour under certain biased attitudes, myths and misconceptions, their interventions can be said to be characterised by this bias.

CONTRIBUTIONS OF THE BEHAVIOURAL SCIENCES

Many behavioural sciences, particularly psychology, have been concerned with disability. Psychology has contributed tremendously to our understanding of issues pertaining to intelligence theory and testing, learning theory research and social aspects. However, within a positivist model of science, using concepts of normative assessment, whereby an induvidual's abilities have to be measured in relation to others in a competitive manner, psychology has joined forces with the clinical perspective in the sustenance of the exclusion principle (Skrtic 1986).

INDIGENOUS PERSPECTIVE ON DISABILITY

This section of the paper focuses on the traditional norms in non-Western cultures, including those in Africa, as they relate to disability. It is important to point out that contrary to popular belief traditional norms and cultures have always been dynamic and have hence enabled people to cope with changes and maintain strong senses of continuity. Within traditional systems *normality* is just as subject to change as anything else. In this inevitable wind of change, there are two important generalisations that warrant mention with regard to traditional or indigenous norms in non-Western cultures. One of these is that a person has a very special, intimate and wholly integrated relationship with the environment. He/she sees himself/herself as a part of the natural world around him/her, and in many instances, actually functions efficiently as a part of the total ecology. Another such generalisation, which also relates to the technological level, is that a person's survival has had to depend on other people around him/her. Both wealth and security are ultimately defined in virtually all these cultures as *people* or often, more specifically, as *family* (Turnbull 1974). Traditional norms in non-Western cultures aim at providing for each individual member of the extended family according to one's needs and each is made to contribute according to ability and capacity (Ozoji 1988: cited by Kisanji 1996). Hence, grandparents, aunts, uncles, brothers, sisters, nieces and nephews are required to be part of the socialisation process of all children in the extended family, regardless of whether they have special needs or not. As Serpell et al. (1993) rightly note, this support system within the family and local community is evidenced in child rearing practices and customary education in Africa. A similar support system has been noted in Asia and Latin America (Sechrest et al. 1973) and among North American Indians (LeFrance 1994).

Writing on the *African Condition*, Turnbull (1974) also alludes to the central position of the family:

> And it is the family that concerns all those dealing with the health and welfare of either the society as a whole or of the individual. Yet, we non-Africans persist in imposing our own fixed notions of family as though our own conceptual framework were the only possible one. (243)

Unlike Western theories of socialisation, which emphasise the development of independence, non-Western cultures tend to be more concerned with the promotion of social responsibility. Hence, a person is defined or understood only in relation to another person or persons. The child with disability is not excluded from this system of values and *growing up* (Kisanji 1996). The concept of inclusion in the field of disability in these non-Western cultures is therefore not something new but a lived experience. The indigenous approach is holistic in that it caters for every individual regardless of disability and does so in the context of social relations. Unlike the biomedical approach, which alienates persons with disability as sick people warranting a cure, the indigenous perspective normalises disability. Differences in ability among persons is something acceptable and to be addressed within a context of diversity. Using Mittler's (1979) slogan, disabled persons are seen as "people not patients" in the indigenous context. While the biomedical approach depicts disability as something that must demonstrate observable characteristics that are verifiable and quantifiable, the indigenous perspective has been accepting of ways of knowing that may not be verifiable by positivism's limited version of science. Disabled persons, their families and allies have advocated this view, identifying disability as a "social and political category" involving "practices of regulation and struggles for choice and power" (Barton 1991: 5). By embracing other ways of knowing, the indigenous perspective does not elevate a small group of people as *knowers*, *experts* or *gate-keepers* to the treasury.

INDIGENISATION OF THE BIOMEDICAL APPROACH TO DISABILITY

The foregoing debate on the biomedical versus indigenous approaches to disability portrays them in a polaristic way. However, while the two perspectives provide very different, if not conflicting frameworks of construing disability, they both contain valuable elements, which if integrated would result in a big step ahead in coming up with a perspective that normalises disability. If the principle of inclusion is to be realized, the biomedical approach should be flexible enough to incorporate some of the indigenous values of family life and childrearing. These values are: respect for every person regardless of their social status or disability and promotion of social responsibility towards each other. Although the extended family is an endangered institution due to urbanisation and migration from rural to urban areas, it is still central in the provision of care and support to its vulnerable members. Hence, policies must be put in place to support the family in working effectively.

As already indicated, another important consideration that needs to be noted is the recognition that there are other ways of knowing that may not be verifiable by positivism's science. To achieve this, the first step involves the recognition by professionals that their world-view may not be shared by the people they serve, induding the disabled. The second step involves granting the disabled and their families the power to be considered as experts in their own area of competence. Professionals who work with disabled people should possess basic underlying attitudes of genuineness, respect and empathy (Rogers 1986). In other words, they should relate to disabled persons and their families as people first and professionals second (Hornby 1991). They also need good interpersonal communication skills in order to work effectively with the parents of the disabled. Those who have had an opportunity to work with parents of disabled children are shocked at how disillusioned and disgusted they are with the lack of sensitivity by most professionals. A number of them moan: "they get this training, but they don't really know how you feel". Ballard (1995: 53) has given excellent accounts of his involvement in action research in New Zealand, which took parents as the starting point. The project involved 143 families and 74 professionals and centred around issues in education, health and welfare. lt was parent-driven. The role of the researchers was to access and provide resources and to be participants in the reflection-action cycle that is an essential part of this approach. The family network activities focussed on information, support, advocacy, networking and training professionals.

Another kind of research that Ballard (1995) reports is *Research as Stories*, learning from experience, which was on intellectual disability. The work involved self-advocates and other adults who had intellectual disabilities, parents and the extended family of children who had intellectual disabilities, and Maori and European researchers. Their goal was to write personal accounts of the lived experience of disability in New Zealand. Action research is very important and should mark our way forward as professionals, and as Ballard (1995: 60) rightly notes, "those with an authentic voice should control the research agenda". Disabled people and their families know best how it feels to be in their situation, therefore they should be given the power to articulate their needs in their own voice. The relevance of this paper and other similar contributions should be seen as attempts to help see that justice is done – that persons with disability decide their own fate and that our role should simply be that of allies. Another way forward is to embark more on anthropological methodologies in our research in the field of disability. We need to learn more about different cultures in the context of disability. Finally, there is a need to bridge the gap between disciplinary perspectives as well as diminish disciplinary friction. Efforts targeted at disability within a profession, in isolation from meaningful interdisciplinary collaboration, often result in less effective delivery of services to the disabled.

CONCLUSION

In conclusion, it should be noted that professionals have public interest obligations. Several factors limit the response of professionals to the needs of the disabled. This paper's plea is that as professionals, we need to change our strategies in the execution of our work. Real inclusion can only be achieved by incorporating some of the indigenous elements in our biomedical approach to disability. The key to helping families with disabled children/persons, then, is the acquisition of favourable experience with the situation. As much as possible, the professional must try to come to see the world through the eyes of the affected family.

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THE USE OF NON-WESTERN APPROACHES FOR SPECIAL EDUCATION IN THE WESTERN WORLD: A CROSS-CULTURAL APPROACH

Friedrich Albrecht

Discussions of North-South relations are persistently concerned with the demand for cross-cultural dialog. *Cross-cultural* means that which lies between the cultures and affects them all. To engage *in dialog* means, among other things, discovering what possibilities for development exist between ourselves and the individual and collective *Other*. Inter-cultural dialog also means asking the question of how we construct our own social reality. To what extent do I recognize in the confrontation with the cultural and social *other* the relativity of my own cultural "system of co-ordinates" (Reimann 1991: 240)? To what extent do I define, as part of my culture, the relational circumstances between subjects, for example, the relations between people that we label as disabled and able-bodied as being more or less natural, although they are socially organized and culturally mediated and reproduced? Also, to what extent do conclusions result from this process that are worth looking at within our own context in terms of keeping or changing elements of our own culture? According to the demands of dialog, an intercultural exchange, an encounter, co-operation or research must go beyond a "simple exchange relationship in which knowledge is reduced to a commodity" (ibid.), to what Erdheim calls a "cultural achievement" in which both participants become partners in a relationship (cf. Meiser 1995: 22).

This means that findings are not produced by one side but arise in terms of a relationship in which the "foreign culture ... initiates a process through which one becomes conscious of one's own typical cultural patterns" (ibid.). The question "What significance do other systems of explanation of disability have for work with disabled people in the Western world?" has, in this connection, much less technical than culture-educational importance. Ethno-psychoanalysis has introduced the nice concept of *the other as mirror* to describe this process. Irrespective of these kinds of reflections on the reciprocal effects of inter-cultural communication another legitimate question arises. This is the wholly pragmatic question "Of what use to me is the view beyond my own cultural horizon in terms of concrete and usable findings relevant for our educational or theoretical system and pedagogical practice?" In the comparative study of education, such an approach is described as *ameliorative*. As examples from Special Education, the comparative studies that were undertaken within the framework of the German discussion on integration in the 1970s and 1980s in Italy, Denmark and other countries are referred to here. To a considerable extent the results of this research contributed to the successful efforts, in terms of policy and educational practice, to integrate disabled children into the regular schools and preschools in Germany.

The value of comparative research on school integration of children with disabilities in similar cultures, like Denmark or Italy, is immediately apparent. However, in relation to Yupno in Papua-New Guinea, the Shona in Zimbabwe or the native inhabitants of highland Ecuador, the question arises of what significance, beyond the rhetorical, can the knowledge of non-Western explanatory approaches to disability have for health-education here in Germany. I will now attempt to point out that, firstly, on the basis of cross cultural comparisons, we can expect to derive no direct applications for use in a Western setting and, therefore, we must search for the key to progress within our own cultural context; secondly, but ultimately, having a *look over our own cultural horizon* can be very useful for us in indirect ways. In support of this assertion, by way of example, see the comparative study by Ute Meiser on the significance of the father in the raising of disabled children in Germany and Tonga.

THE FIRST THESIS

In connection with the social and cultural integration of disabled people, Benedicte Ingstad (1991: 14–15) has addressed two widely circulated myths. The first she calls the *Historic Myth,* which bears the assumption that, in the Europe of the past, a disabled family member was seen as a disgrace or as a punishment by God and, as a result, that the disabled relative was hidden away or killed. The message contained in this myth is: *A society's modernity promotes the acceptance of disabled people*. The second – and more recent myth – she calls the *North-South Myth*. This myth has arisen as a result of supportive measures in the disability field between North and South. Here also concepts like shame, concealment and killing are emphasized in order to attract attention and to legitimate assistance measures. *Let the developed societies teach the underdeveloped nations how to integrate people with disabilities* is the message of this myth.

I will now bring into play yet another myth of the opposite tendency. I name this the *Myth of Better People in Other Places*. It is characterized by a mixture of fascination with the exoticism of the foreign on one hand, and by a culturally and socially critical attitude towards one's own background on the other hand. Our gaze, directed at the exotic culture, succeeds in locating – I exaggerate here – what one might call the key to the rescue of the West. The world would be a better place if only we would live in harmonious extended families, and in harmony with nature, and stop striving so hard for material goods. The message here is: *Let us find more humane ways of dealing with the disabled than isolation and segregation*.

It is precisely this traditional model of community, clan and family orientation that appears to offer a potentially successful alternative to the practice of segregation, seen as a developmental deformity of industrial culture, out of which the *disabled person as a defective being* was constructed. In the Western view, the disabled person is seen as useless for the production process and is therefore excluded from the social and economic system. In contrast to this, we can assume that traditionally oriented cultures totally lack a belief corresponding to our *disability as a general concept*. They distinguish, to be sure, between the blind, lame and senile etc., while recognizing that all these types of people have something in common. However, a grouping of all of them together as part of a higher and overarching category does not develop. This fact is very interesting because it suggests that, in traditional cultures, physical, mental or psychological deviation represent no compelling reason to construct *We and They groups* (in the sense of able-bodied versus disabled people). With the construction of *We and They groups* societies and communities determine their inside and outside and, as a result, who or what belongs, or is marginally included or is excluded from that community or society. The decisive choice of categories – according to Frank Olaf Radtke (1991: 79) – "dependent on the dominant problems of order and rank in a society".

A socially distinct group called *disabled* is constructed in a society when a physical, mental or psychological deviation is seen as a valid indicator that a problem in the social order exists. Consequently, a society regards as problematic the questions of if and how people with these characteristics are to be educated, how to integrate them into the work process and how to allow them to participate in normal life. To solve these problems social processes of special treatment develop, at the center of which the characteristic trait or the complex of characteristics is located. This means that the problem, in terms of its origin and in an educational and therapeutic sense, becomes attached to the individual.

The situation is different in traditional cultures. Individuals who in our industrial culture would be identified as disabled or impaired are indeed recognized, but no separate social categories are constructed for them. From this we can conclude that problems of order do not tend to arise in relation to the symptom, but rather that impairments or diseases are included in the frameworks used for the processing of other problems of social order. For example, a significant problem of social order in traditional cultures is the manufacture, or the re-establishing, of harmony in social relations. This need to establish and re-establish social harmony arises from the fact that social relations are subject to a multiplicity of human, natural and, above all, supernatural influences. People's lives are based on their relations to other members of their family, clan or community. They also have social relations with witches, spirits and ancestors. There is no basis in this situation for individualizing the problem of disability. In traditional societies, where metaphysical explanation patterns and traditional knowledge determine the perspective on those who are different, impairment is always a matter that also affects the family, clan or society as a whole. For the impaired person this situation can have quite positive effects. Thus, for example, the causal explanation of *ancestor intervention* can lead to the disabled person being handled in an affectionate and accepting way. She or he is treated by experienced healers, using traditional methods, and is accorded a place in the extended family. The disabled person serves a useful function in the family in the sense that the ancestors, who have been angered by the breaking of a taboo, can thus be pacified and the community protected from additional misfortune (Albrecht 1997: 167–168).

What can we conclude from the findings that, in traditional cultures – in complete contrast to what the North-South myth implies – forms of social organization, healing procedures and educational systems are *also* available that encourage the inclusion of people with disabilities. (I emphasize the word *also* because exactly the opposite can be true, for example in the case of severe defects.) In my opinion it is obvious that any conclusion, based on a simplistic interpretation of such findings, is pointless. Our goal, therefore, is not a direct practical application of cross cultural research findings. This is because education as a "reaction of society to the facts of development" (Bernfeld 1994) is culturally determined and therefore can only be viewed in the context of very culturally specific ways of seeing and doing things.

> We cannot wander at pleasure among the educational systems of the world, like a child strolling through a garden, and pick a flower from one bush and some leaves from another, and then expect that if we stick what we have gathered into the soil at home, we shall have a living plant (Sadler, cited in Schriewer 1998: 192).

This statement is taken from a lecture given in 1900 by the English educational historian and politician Michael Ernest Sadler. The title of his lecture was "How Far Can We Learn Anything of Practical Value from the Study of Foreign Systems of Education". Sadler thematized, for the first time, in his content-related and methodological self reflection, the inquiries and problems of the young discipline of comparative education. Thus, he undertook the first criticisms of the then dominant *foreign pedagogy*, with its descriptive and eclectic character. In the background he is also asking the "question of *in what way* and *how* are things different in other places, to the benefit of the larger question of *why* are things different in other places" (ibid.). His argument: the premature search for something that we can use makes us lose sight of the historical and cultural context of our research object and, as a result, makes objective and scientific findings impossible.

The plant growing in its native soil is thus not directly transplantable and can, if at all, only be reanimated by means of an indirect approach that takes into account the culture-historical preconditions of the foreign *and* those of our own culture. To put it more exactly: answers to the question "Why is it different there?" simultaneously produce answers to the question, which arises at the same time, of "Why is it different here?" The conclusions which follow, about the ways in which change can be pursued, are therefore only to be found in the context of our own culture. However, the act of looking beyond the familiar horizon can help us to be able to formulate the necessary questions.

PROCEEDING TO THE SECOND THESIS

To arrive at practical applications indirectly, Sadler formulated three ways to realize goals that have remained a major component of the goal and task catalogue of comparative education up to the present time. These are:

1. *the comparative study of education as a medium for conveying scientific-pedagogical knowledge*, which means the widening of the perceptual horizon for better understanding of our own pedagogical reality;
2. *comparative education as a potential stimulus for practical pedagogical thinking*, which means the encouragement of imagination in teaching, which can inspire suggestions for making improvements; and
3. *comparative education as a stimulus for international competition in education,* awakening a readiness for reform (see ibid.: 193).

With a view to the ways in which findings on explanation schemata for disability in traditional cultures might be used to alleviate suffering, the first approach seems to me to be most significant. At this point, I would like to deal with this first approach and present a case study as an example. In her study, Ute Meiser compares the cultural significance of the father in the early development and training of children with disabilities in Tonga and Germany. Her starting point are her own *confusions* which arose during her almost two years of field research in Tonga. There she was confronted with patterns of behavior which are lacking in our own culture. Concretely, her confusion was a response to the fact that, there, fathers are actively involved in the process of their sick children's healing and take responsibility for the child's care. They talk about their ambivalence, feelings and fantasies, express worries and fears, and work through these feelings in the process of active participation and through their constant contact to the affected child (see ibid.: 82). Initially in her fieldwork, Meiser did not explicitly look at the role of the father – she was interested in how illness and disability in general was dealt with in Tongan culture. And in a completely ethnocentric way, as we all would do, she planned to conduct interviews on the basis of expectations that she had brought with her to the field. One expectation was, "That only the mother would or could make highly specific statements about the care, illness and early childhood development of the child" (ibid.: 74). However:

> It is the fathers who appear with the infants, the fathers who talk about their children, and the mothers went to fetch their husbands from the plantations when there were questions about early childhood. One Tongan woman told me that she was unable to answer many of my questions in detail and would have to call her husband. He had mainly looked after their daughter at the time, while she was working in an office in town. (ibid.)

Based on initial experiences such as this, and using her background of field and literature research, Meiser painted a picture of an *androgenous male role* in Tonga. This androgenous male role permits the Tongan father to play an equally significant role in child care and training in general, and in the case of illness or disability in particular, to be equally important in the process of treatment and dealing with the disability. The assumption of such a role is important because the treatment of illness aims at involvement of the entire family. Should a person become ill or disabled, Tongans are convinced that this is the consequence of the breaking of a taboo or of a conflict with a person of authority within the family. The curing of the illness usually begins with the family trying to find out which taboo has been violated, thus causing the problem to occur. Dreams are reported and interpreted, various healers are consulted and their diagnoses compared. The ongoing treatment includes herbal medicines and encourages collective expressions of grief, for example through group weeping. As part of the process, discussions about conflicts within the group are held, which make reparations for the taboo violation possible. The principle of pardon is the key to the curing of illness. Healing can occur when taboo violations are recognized, apologies are made, and pardon is granted. If an illness or disability becomes chronic, on the other hand, it is seen as an indication that an offending behavior has not been admitted and pardoned (see ibid.: 79–82). According to Meiser, these curing practices "resolve conflicts, are ego-stabilizing, promote group solidarity and are ego-supportive and adaptive through ritual" (ibid.: 81). Fathers are just as integrally involved in these curing practices as they are a major aspect of the identity development of their children. Confronted with these findings, she presents another picture of fatherhood for Western culture. Except for a few cultural niches, the father is part of a gender antagonism in which the man is unconsciously assigned to the realm of culture (and its progressive development) and the woman to the realm of the family. In crisis situations, such as the care and supervision of a sick or disabled child, this antagonism manifests itself dramatically and leads to a chronic traumatization of the family situation. This hinders the family from adequately dealing with the situation. The father becomes even more externally oriented and the mother even more focused on the interior world of the family. The androgenous role of the father in Tonga stands in contrast to the father's "role as the representation of the outside" in today's cultural sphere, the main function of which is "setting boundaries to help to dissolve the mother-child symbiosis" (ibid.: 85). In this role, the father appears as a *"liberator"*, bringer of awareness and savior, sometimes as a *trouble-*

maker or even *foreign body.* "As the third object and representation of the outside world" he is as a result, according to Meiser, "largely excluded from intimate experiences of the early phases of his child's life" (ibid.: 87). Thus, she asserts that:

> As long as the father remains the third object and representation of the outside, he will retreat to the exterior world in situations of conflict and will *fail*, for example, as a care giver and source of emotional support for a disabled child (or refuse to fulfill this role). The mother, who is responsible for child care, and considered *competent* in this family related activity, is overburdened by the task and is unable by herself to manage the failures and emotions – especially her aggression – that are associated with it. (ibid.: 91)

This *reduction by half* of the woman (to the world of the family) in our culture corresponds to *reduction by half* of the man (to the world of culture) with its associated psycho-social effects.

The emphasis on the idea of culture I find very appropriate in this connection. In my opinion, these reductions of the male and female personalities cannot be completely explained in socio-economic terms. They are also part of what we have appropriated from our cultural milieu, of how we internalize the world and accommodate ourselves to it.

CONCLUSIONS

The value of such culturally comparative work – as I have already emphasized – cannot lie in specifically stressing the exemplary character of foreign systems of explanation and ways of doing things. Tonga is not only geographically but also culturally *too far away* for that. However in the sense of the first of Sadler's approaches – to arrive at a better understanding of the conditional nature and the problems of our own educational system – comparative studies are quite helpful. This is because they can represent a stage in a process of perception, through which the relativity of our own cultural system and its mechanisms can be revealed. I see the cross-cultural perspective – a modest attitude is called for here in my opinion – as adding to and complementing the *intra*-cultural view. The central theme of the study offered here, as an example, is the disclosure of the Western antagonism between the genders and the consequences of this antagonism for child rearing. Meiser wants to "make the emotional deficits that are characteristic of our technologically determined culture more conscious, especially those that manifest themselves in child rearing" (ibid.: 90). She succeeds in this because her analysis relates to, or can relate to, the findings of research in the area of feminist pedagogy (see Prengel 1993: 96–137) or to the medical pedagogical research on relational disturbances of families with disabled children.

In our middle class society, the technological development in the health-educational and therapeutic care of people with disabilities has made enormous progress. In contrast to this progress, the structures of social support for families with disabled children, in dealing with usually enormous psychological and physical burdens that result for the parents, still adhere to a pattern that has its origins in the development of bourgeois society. The father compensates through his job and external social relations (since he represents the goal orientation and rationality of the male gender). The mother compensates through the family (since she represents the moral gender)! Thus the father is pushed even more into the spheres identified as male (more time spent on the job, more handy-man tasks in house and garden, more socializing at the club or bar) and the mother even further into hers (more attention and love, more co-therapy, more play and mothers' groups).

We have arrived at a point that seems to offer a good place to conclude the discussion. This is the thesis that questions of how to advise and support mothers and fathers have received too little attention in health-educational developments in Western societies and, as a result, a one-sided arrangement has been made that is too focused on instructional-therapeutic procedures. All else would either be purely speculative or require research that cannot be performed within this framework. This thesis, as well as its possible consequences for educational-therapeutic practice (for example for self-help-, adult educational-, child rearing- or parental counseling concepts), requires a debate that is better grounded scientifically. What I wanted to achieve in this contribution was much more to show that the indirect usefulness of cross-cultural comparative studies lies in calling into doubt our own, culturally specific, mechanisms and thus stimulating reflection, not just about other cultures, but also about our own society.

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CONCEPTS OF DISABILITY WITH REGARD TO MIGRANTS

MEANINGS OF DISABILITY FOR CULTURALLY DIVERSE AND IMMIGRANT FAMILIES OF CHILDREN WITH DISABILITIES

Maya Kalyanpur

THE MEANING OF CULTURE FOR IMMIGRANT FAMILIES OF CHILDREN WITH DISABILITIES

Special education is a product of its culture. First, as microcosms of the macro-culture (Tyack/Hansot 1982), schools share the same values of individual rights, equality, personal choice, hard work, and social mobility that are highly regarded within the dominant American culture (Spindler/Spindler 1990). Special education, an equity measure for students with disabilities who might otherwise be at risk of academic failure, is an aspect of this microcosm of regular education. Further, it adheres to the same epistemology of Western rationalism and scientific objectivity as regular education. As the U.S. rapidly becomes the most multicultural society in the world, it is important for professionals to examine these embedded beliefs in special education. This paper attempts to deconstruct the value base on which professional knowledge in American special education is built to advocate for a level of cultural awareness that can radically alter the ethnocentricity with which we usually approach families and communities which diverge significantly from the culture of special education. It identifies the implicit assumptions of the dominant paradigm of special education epistemology, the medical model, and analyzes the implications of these assumptions for families from contrasting traditions.

CULTURAL UNDERPINNINGS OF SPECIAL EDUCATION EPISTEMOLOGY

The paradigm that has dominated professional knowledge in special education is the clinical perspective, or the medical model (Mercer 1973). This perspective of deviance contains two contrasting theories of normalcy: The pathological model defines abnormality according to the presence of observable biological symptoms, and implies that abnormality is an unhealthy state that requires alleviation or *fixing*. The statistical model defines abnormality according to the extent to which an individual varies from the average of a population on a particular attribute. The clinical perspective of disability yields four implicit assumptions: disability is a physical phenomenon; disability is a type of chronic illness; disability is individually owned; and, disability is a condition that requires *fixing* (Bogdan/Knoll 1995; Skrtic 1995; Mercer 1973). This section examines each of these assumptions and their implications for families from contrasting traditions.

Disability as a Physical Phenomenon

According to the field of medicine, a disability is assumed to have a biological etiology and an identifiable set of symptoms that constitute that disability; in turn, any individual who exhibits a minimum number of symptoms characteristic of a particular syndrome is assumed to have that specific disability. The medical model in special education assumes that characteristics specific to some students account for their need for specialized instruction. For instance, the official definition of learning disability views learning difficulties as intrinsic to the child by explicitly excluding environmental, cultural, or economic effects from the definition (IDEA 1997).

Disability as a Chronic Illness

The Western rationalist dichotomy between spirit and body informs the medical model's focus on the corporal aspect of being and imputes all etiologies of disability to biological dysfunction (Zola 1986). Further, should an individual have a disability that will prevail throughout his or her lifetime, the condition is perceived to be chronic. Western time is both linear and abstract. In contemporary Western societies, time is a finite, measurable resource. In finite clock or calendar time, disabilities are perceived to be the results of events that have occurred in individuals' present lifetime. Since death provides the end to this finite life, by definition, a lifelong condition, such as a disability, is one that persists through an individual's lifetime. Special education and rehabilitation policy is based on this understanding that a single lifetime is all the clock time individuals have to maximize their potential. Further, in clock time, the future is a dimension that occurs within the present lifetime – a belief that forms the underpinning to the legal requirement of transition planning.

Disability as an Individual Phenomenon

In mainstream American culture, a medicalized explanation of disability is generally seen as mitigating stigma, since the condition is viewed as an accident of nature, an event beyond our control for which no-one can be blamed. Further, it locates the problem within the individual rather than the family, unless there is clear evidence of genetic etiology, such as with fetal alcohol syndrome. Monks and Frankenberg (1995) suggest that this focus emerges from the notion of personhood in Western industrialized societies wherein "the location of individuality in consciousness has been associated with an emphasis on rationality, responsibility, and the continuity of a self that exists independently of both the sociocultural environment and bodily changes" (ibid.: 107). Thus, special education attributes a child's failure in school to some flaw within him or her – most notably, an insufficient IQ – rather than inadequacy on the part of the educational institution (Bogdan/Knoll 1995).

Fixing the Disability

Special education and rehabilitation are based on the premise that disability is a problem that needs to be and can be *fixed*. Further, since it is assumed that the disability is intrinsic to the child, interventions are geared exclusively towards remedying this condition within the child, ignoring the impact of environment (Bogdan/Knoll 1995). Two cornerstone tenets of special education, normalization and behavior modification, emerge from these assumptions. The understanding is that individuals with disabilities can be *normalized* if provided with the repertoire of settings and activities that typical nondisabled peers would have access to, and, through a process of behavior modification, taught the skills for successful participation, however partial, as well. In other words, given the opportunities to attain the same outcomes of life as their nondisabled peers, individuals with disabilities will have socially valued roles.

CONTRASTING TRADITIONS OF THE MEANINGS OF DISABILITY

Many cultures lack the level of abstraction and belief in the immutability of science that characterize Western cultures (Hall 1976), which contributes to an alternative perspective of disability, the social systems, or the community perspective (Mercer 1973; Edwards 1997) where "the meaning of impairment must be understood in terms of cosmology and values and purposes of social life" (Whyte/Ingstad 1995: 10). In this context, disability has no inherent meaning but is defined by any given community's understanding of people's roles, and the degree to which one is able to fulfil the tasks of membership determines the degree of one's physical ability or disability (Edwards 1997; Talle 1995). For instance, while certain descriptors, such No-Eyes in many American Indian tribes (Locust 1988) or *dhegoole* for without ears in Somalia (Helander 1995), imply a set of conditions, the image intended by the term varies from usage to usage, informed by the context (Edwards 1997; Talle 1995) and is not meant to signify the individual as being a member of a category of *disabled people* (Chan 1986; Helander 1995; Locust 1988). Further, the value attached to a specific condition varies among families, in terms of whether it is perceived as disabling and/or stigmatized. For instance, among many Hmong families, epilepsy is neither a disability nor stigmatized, but an illness of "some distinction ... , and a sign that the person has been chosen to be the host of a healing spirit" (ibid.: 21), a position of high social status (Fadiman 1997).

In this section, we examine four assumptions made by the social systems perspective that contrast with those of the medical model. These assumptions are: disability is a spiritual phenomenon, disability is a group phenomenon, disability is a time-limited phenomenon, and disability must be accepted. In noting that the assumptions of the social systems model contrast with those of the positivistic medical model, we mean that they emerge from a set of values that is often diametrically opposite to those imbedded in Western rationalist thought, and not that they are irrational.

Disability as a Spiritual Phenomenon

Adherents of the social systems perspective do not necessarily rule out the possibility of a physical etiology to a disability; the difference is that they may also ascribe spiritual or sociocultural causes (Danseco 1997; Serpell/Mariga/Harvey 1993). For example, while many Hmong (Meyers 1992; Fadiman 1997), American Indian (Locust 1988), and Punan Bah (Nicolaisen 1995) families impute to illness a natural cause, such as old age or eating unsuitable food, the most common cause of illness is soul loss, or *ghost sickness* (Locust 1988: 321). In Fadiman's study (1997) of a Hmong family whose daughter developed epilepsy, the parents attributed the condition, which they referred to as the sickness in which "the spirit catches you and you fall down", to soul loss caused by fright. Similarly, the Mexican-American families in Mardiros' study (1989) attributed their child's disability to both biomedical causes, such as chronic health problems during pregnancy or pollution, and to sociocultural beliefs such as marital difficulties and divine punishment for parental transgressions.

The 'evil eye', curses, and other metaphors of spiritual malevolence are also seen as common causes for sickness and disability among many Maasai (Talle 1995), Hmong (Fadiman 1997), Jewish-Oriental (Stahl 1991), American Indian (Locust 1988), Latin American (Groce/Zola 1993), and Hubeer families (Helander 1995). These spiritual concepts have a distinct social component and are believed to have been triggered by some neglected duty or obligation of the victim. In the case where the victim is a child, the cause may be envy from those less fortunate (Helander 1995; Devlieger 1995). As a result, many deem it a bad omen to express admiration for anything good, like a large and healthy family (Talle 1995; Fadiman 1997). This belief in the concept of the 'evil eye' impacts on the families' responses to illness and disability, including beliefs about causes and treatments sought. For example, some Maasai families distinguish between congenital anomalies which are seen to be caused by a divine curse, an act of God, and acquired disabilities, which are caused by sorcery, a human act, in response to a social transgression; whereas nothing can be done about the former, the latter condition might be ameliorated through the services of a shaman and/or by righting the wrong (Talle 1995).

Another spiritual explanation for a disability is that it is direct evidence of a transgression in a previous life of either the parents or the child, a belief strongly held among many Southeast Asian (Danseco 1997; Chan 1986) and Indian (Groce/Zola 1993) families who believe in re-incarnation. To many Mexican American (Smart/Smart 1991), African American (Rogers-Dulan/Blacher 1995) and Tswana families (Ingstad 1995) their child with disabilities is a gift from god. Among many Songye (Devlieger 1995) and Hmong (*Hmong family* 1991) families, a child who is born with certain characteristics will sometimes be considered to be an ancestor who has come back into the family, that is, the child is said to be born with "the spirit of the ancestor" (Devlieger 1995). For example, in the case of a child born with a club-foot, the Songye interpretation was that the ancestor was not well buried, too small a coffin causing the feet to be squashed (Devlieger 1995: 101-102), while the Hmong interpretation was that the ancestor had been wounded in the foot in a battle (*Hmong family* 1991).

Disability as a Time-Limited Phenomenon

Beliefs about the causes of disability can affect families' perspective on whether a condition is chronic. Among many non-Western cultures, time is cyclical and, therefore, infinite (Fadiman 1997; Locust 1988; Meyers 1992; *Hmong family* 1991). The past, then, is not necessarily that period of time that occurs between an individual's birth to the present moment, as might be understood in most Western cultures, but also the preceding period which includes previous lives (Fadiman 1997). Similarly, the future need not be the period between the present and the moment of death, but can include the period following the death of the corporal body, where the spirit will go on to inhabit yet another body (Locust 1988). Those who see a spiritual explanation for the disability, such as soul loss, view the child's condition as temporary, with the hope that either the soul will be recalled (Fadiman 1997) or the child outgrow the problem (Smith/Ryan 1987). Danseco (1997) notes that among families who believe in reincarnation, "disability is perceived as a temporary condition when viewed along several possible lives" (ibid.: 44), the disability itself seen as the result of an event in a previous life. This notion of cyclical, infinite time makes future planning an exercise in futility. Further, to plan for the future is to assume a certain life expectancy that may be inappropriate, especially for an individual with a disability (Whyte/Ingstad 1995), or appear as if one were unappreciative of the present (Locust 1988; Cunningham/Cunningham/O'Connell 1988).

Disability as a Group Phenomenon

A tacit understanding in all these nonphysical explanations of the causes of a disability is that the child is not solely responsible for its occurrence, but that the entire family is implicated. For instance, many American Indian tribes believe that while a spirit may choose to inhabit the body of a handicapped person for some purpose that the spirit and the Supreme Creator have determined, the causes of a body's being handicapped, and consequently the blame lie with the parents (Locust 1988). Similarly, many Maasai families believe that, although the supernatural punishment for an ancestor's sins, such as dereliction of duty towards one's parents, comes in the form of the disabled child, the child itself cannot be blamed for it (Talle 1995). Many Tswana families refer to a child with disabilities as *mopakwane*, a condition believed to be caused by breaking taboos against sexual intercourse during confinement, a label that stigmatized the parents, not the child. Again, among many Songye families, disability is made a relational problem between human beings and the occurrence of disability in the family the starting point for an inquiry into the relations of the family; the assumption is that "the problem of disability is not a problem of the individual but rather a problem of the family" (Devlieger 1995: 100-101).

However, there are positive and negative implications for this perspective of group responsibility. On one hand, the stigma attached to a condition affects the entire family. On the other, the stigma is mitigated by a holistic view that interprets disability and illness in terms of family rather than individual traits (Harry/Kalyanpur 1994; Kalyanpur/Rao 1991). For example, in Harry's study (1992), the Puerto Rican American parents tended to describe individual difficulties in terms of a normal range of diversity within the family pattern, allowing for a less stigmatizing interpretation of a child's slowness in reading or a quick temper as being *just like his aunt*, or *just like her father*. Similarly, many Asian families often interpret their child's school-based difficulties as *laziness*, oppositional behavior, or indications that they may not have trained their children adequately (Chan 1986). Another positive aspect of group responsibility is the collectivistic support that becomes available to the family. For example, Locust (1988) notes that:

> (Native) Indians believe that an individual's spiritual illness can affect the group (family and friends), and thus group efforts are required to return all members of the group to wellness. As a result, students who are not ill may be absent from school in order to assist a sick relative in returning to wellness. Although this group effort is of vital importance to tribal, clan, and family members, it often becomes a point of antagonism between group membership and school officials, resulting in discriminating actions by school authorities. (ibid.: 319)

ACCEPTING THE DISABILITY

A family's perceptions of the cause of disability impacts greatly on whether they will seek help, and the types of interventions they seek (Danseco 1997). Reasons for accepting the disability are many. For instance, a study of familial attitudes in Africa (Serpell/Mariga/Harvey 1993) found that families who attributed a condition to witchcraft, an act of god, or natural causes were likely to seek help while those who linked the condition to family ancestors tended to accept it without seeking external help. Similarly, among many Maasai families, a disabled child is a fact of life which must be accepted, and statements like "we met him just like that" (referring to a child who was born disabled) convey the message that the child's impairment is an act of god that is beyond human comprehension and ability to cure (Talle 1995: 62). Again, the belief among many Hmong families that the body must be whole to reincarnate as a whole being compels them to reject invasive medical procedures like surgery, prostheses, dental fillings, and autopsies (Meyer 1992; Fadiman 1997). The belief among many Hubeer families that individual deviance is given "cosmological sanction and religious legitimation by the astrological system" facilitates a fatalistic acceptance of the disability (Helander 1995: 75). It is important to note, however, that most families do seek intervention, the type of service often depending upon what is perceived to be the cause of the disability. For instance, in their study of African families (Serpell/Mariga/Harvey 1993), the authors note that families who attributed a condition to an act of god were more likely to seek help from a modern medical facility, while those who believed that witchcraft was involved were as likely to visit traditional practitioners as a medical facility. Similarly, the Hmong family in Fadiman's study (1997) treated their epileptic daughter with the anticonvulsants prescribed by American doctors and a soul calling ceremony to retrieve the soul that was performed by a traditional health care practitioner, a shaman. Among Songye families who believe that disability is a response to disharmony in the relationships among family members, the father of the child with the disability may ask his wife to redistribute her bridewealth among the members of the family towards restoring harmony (Devlieger 1995). Helander (1995) notes that many Hubeer families as a measure might initially seek different medicines or healing techniques, both traditional and modern, but the few, if any, results and the cumulative costs of health care combine to fuel feelings of despair and resignation, at which point the terms *naafo* or *boos* are used to describe the person to imply that nothing more can be done.

However, whether families choose to do nothing or seek help, their actions are grounded in an acceptance of the disability. Indeed, among many groups, there is little awareness of the potential for rehabilitating, finding roles, or developing adapted life-styles for adults with disabilities (Helander 1995) and the notion that a child with disabilities can be helped by early intervention or stimulation may not be part of common knowledge, or, in the case of many developing countries, even the standard knowledge base of medical and educational professionals (Groce/Zola 1993; Kysela/Marfo 1984). One factor that accounts for this level of acceptance is the belief in fate or *karma* (Danseco 1997), enhanced when the cause of the disability is perceived to be divine retribution for one's sins. This fatalism has been instrumental in some Christian Scientist families choosing not to seek medical treatment for a child with a life-threatening illness (Fadiman 1997). Another factor is the belief in value-inequality which, by assuming that every individual has his or her own niche within a social hierarchy with its ascribed roles and status, runs counter to the concept of maximization of potential. Attempting to change this status quo by seeking treatment or interventions would be considered tantamount to destroying the existing social equilibrium and harmony, an act that would affect the entire community (*Hmong family* 1991).

Conclusion

Western professional epistemology is based on the assumption that scientific knowledge is objective and therefore universally applicable; this assumption has contributed to the medical model predominating in special education policy and practice. Professional unawareness of the assumptions inherent in the medical model, that disability is physical, chronic, individually owned, and can be fixed, has significant implications for families who may believe, on the other hand, that disability has spiritual causes, is temporary, group-owned, and must be accepted. Believing that disability is a physical phenomenon, professionals may not understand parents who might use the services of a shaman to recall the lost soul of the person with a disability. Believing that disability is a chronic phenomenon that will last through the lifetime of the individual, professionals may not understand parents who do not plan for the future. Believing that disability is an individual phenomenon, professionals may not understand parents who perceive the attribution of a disability to their child as a matter of shame for the whole family. Finally, believing that disability can be fixed, professionals may not understand parents who will not seek any treatment or intervention for the condition.

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SOCIAL WELFARE OR SOCIO-POLITICAL ENTITLEMENT: DISABLED PEOPLE CAUGHT BETWEEN THE POLES OF THEIR TUNISIAN ORIGIN AND ACCULTURATIVE PRESSURES

Mustapha Ouertani

Our society is increasingly socially complex. As a result – often as an initial response to emerging conflicts about participation in all areas of society and government – the view of the differences between the members of society and their needs has become more focused. When we deal with ideas and conceptions about the theme of *disability* from the perspective of different cultures, we are confronted simultaneously with a number of contradictory but closely interrelated aspects. This is especially true seen from the perspective of migration. First of all, it is worthwhile to clearly work out the similarities and differences in the definition of, as well as evaluation and attitude towards, disability. We then need to look at how these arise in the various socio-cultural contexts that people who migrate are involved in. The pressures for acculturation, to which immigrants are already exposed in any case, are even more intense in the case of disabled immigrants. This is because of the confrontation of their own understanding of disability with another such understanding. This other interpretation is experienced as alien and constitutes an initial potential for conflict. This initial conflict is experienced at first as a shock, in that communication and interaction are conditioned by completely different experiences and standards of judgement. In brief, disabled people who are also immigrants are in a fundamentally different situation from disabled people who are Germans.

The understanding of self of the disabled German develops in a socio-political environment in which individualism and independence, as well as an attitude of *stand on your own two feet*, are legally formulated and enacted in law and are, finally, legally enforceable. This clear prestructuring of everyday life is experienced for a while as positive and its predictability is meaningfully applied as a principle by disabled immigrants as a guide in life planning. However, all their earlier psycho-social experience in their country of origin contradicts, in a sobering way, this calculation based on the promotion of individuality. For the cultural group of Muslims who come from a region like North Africa[1], the family constitutes above all the basic cultural, economic and political unit. The family prefigures all communication, interaction and dealings in society and government. The family was and is to be understood as a microcosm of society. This means that the family represents the original, prototypical form of the religious community and is an economic core group. As such, it not only regulates the common family life of all individual members, in its socio-political, cultural and political dimensions, but also the life of the individual down to the smallest details. This is true even today. Outside of this structure it was impossible for the individual to exist. "The family is everything because nothing exists outside of it" (Gu'rin 1906: 105). The family fulfilled its responsibility, for example, by providing employment for family members and by serving as a bank which functioned as a source of capital. Decisions were made by the older men, by fathers. They held all official power and allowed no opposition. Without the agreement of the elders no important decision relating to the interests of the group as a whole could be made. No marriage was agreed to without arrangements in advance, and all other festivities, especially those honoring the revered forefathers of the community, always served to maintain family solidarity.

Even if the Islamic family structure and functions described above are undergoing the same processes of transformation as outlined for families in Germany, they represent a strong authority operating in the background. This is especially true in relation to disabled members. The reason for this is the Islamic code of social ethics, which is systematically set down in the *Qur'an.* As stipulated by this code, the rights of orphans, the disadvantaged and the disabled are protected. This means that the *Qur'an* is concerned with social groups that require the protection and care of the community. On this basis, the inclusion of the disabled person is a necessary and self evident attitude in an Islamic society. Within this kind of family unit, which has maintained a significant degree of stability despite societal change, the disabled person is a fully integrated member of the community. The disabled person is rewarded, not according to performance, but rather on the basis of abilities and needs, just like other family members (Ouertani 1994). This generally positive attitude is an expression of the Sufi tradition in Islam[2], which takes a holistic view of the human being as having physical, psychological and social aspects. Within this perspective, the disabled were taken into consideration in the division and distribution of labor. To a certain extent it can therefore be legitimately established that the attitude of Muslim parents – only natural when interpreted in a typological sense – can vacillate between one of constructive acceptance and support as well as one of clear rejection of disability and of the disabled child (Said 1997). Seen in a general psychological sense, the attitudes of parents towards a disability are not the result of a conscious decision but are the consequence of the interaction of human beings and their surroundings. To a significant extent, these attitudes are determined by factors that are beyond the control of the individual and two facts must be taken into consideration at this point. Firstly, attitudes – just like life in general – are not static but are subject to changes. This means that

> the majority of parents can be helped to express their attitude, recognize it and eventually to change it for a double benefit to their child and to themselves. (ibid.: 4)

Furthermore, attitudes can usually not be clearly defined because they change according to the situation and measure of satisfaction that parents receive through the actions of their children: "Love and hate, acceptance and rejection seldom appear in a pure form" (ibid.: 5). Much more relevant are the levels of the predominant attitudes which characterize the parent-child relationship.

The integration and participation of the disabled in social life appeared in Europe, in contrast, first with the Enlightenment and later with industrialization. Last but not least, the damage resulting from frequent wars made it necessary for the state to take action (Müller 1990: 162–191). As a result of the social movements of the second half of the nineteenth century, led by significant figures in public life like the theologian Hermann Schulze-Delitzsch, and through the influence of social democracy (August Bebel), disabled people – above all the blind – organized themselves into interest groups and attempted to make changes in the laws. Only over a period of several decades was admission to paid employment outside the home made possible and, along with this advancement, a better status in general for disabled persons in Europe, in contrast to the colonies of the European nations. A carryover of these developments to the colonized countries did not occur. Preexisting structures were actually destroyed and replaced with new structures that allowed indigenous disabled people no proper place. The changes in the social structure of the North African populations, taking place in the colonial era as a result of economic pressures, caused a flight from rural areas and the impoverishment of the internal migrants. These developments, along with repeated epidemics, caused the situation of the disabled to deteriorate. Bad sanitary conditions, and the lack of hygiene and job security, actually led to an increase in the incidence of disabilities. Thus, in the immediate post-colonial period in North Africa, disabled people were neither adequately protected by the traditional social safety net, nor could they rely on access to European-style medical care in the urban centers. Although the North African states were subjected to a great deal of pressure to modernize, including the integration of the disabled, the colonial system did not pursue progress in the areas of education and public health with the same enthusiasm as organizing the economy for their own profit. The solution to this problem consisted in creating a European-oriented plan for political advocacy, medical care, academic and vocational training, as well as labor market related policies and measures designed to benefit the disabled. This meant the creation of special facilities for the disabled such as schools, sheltered workshops, vocational training centers etc.[3] At the same time, the traditional family and community oriented concept of social welfare persisted and continued to exert influence. This caused the integration of the disabled in North Africa to proceed along two different tracks and in two directions. It is not only the state that educates, takes care of and promotes the interests of disabled people, the family and community also make strong efforts to integrate them. These efforts are a taken-for-granted part of family and communal life, despite all of the processes of social erosion that have occurred in North Africa. This aspect of family and community, the performance of the task of integrating disabled persons jointly with the state – without leaving it up to the state alone – is gaining new significance in connection with recent discussions about the costs of health care and the cost-related withdrawal of the state from its provision. What light can the comparison of the developments in Tunisia throw on the developments in Germany?

Behind the cuts in funding and jobs in the areas of support and rehabilitation of disabled people that are planned or have been already carried out in Germany is a specific view of disability and disabled people. This view is characteristic of a social order based on the market economy. Since disabled people do not conform to the principle of economic performance, they are the first large group to be subject to budget cuts. The same is true for their integration into the sphere of employment. During economic recessions, the access of disabled people to education, skilled occupations and employment is made more difficult. An indication of this is the statistic of over 100,000 trained disabled people who are unemployed, despite the fact that employers receive a compensation award of 250 Marks a month for hiring handicapped persons to fill positions that would otherwise remain unfilled.[4]

Now for my thesis: these very concrete effects on the lives of disabled people arise from the fiction that society is homogeneous. This is the basis of the belief that disability is an individual deviation, the fate of the individual, and not the result of social interaction and acts of communication (Ouertani 1994: 389). The disabled person is thus measured according to a standard that is imaginary but, none the less, deeply rooted in socio-economic structures and overwhelming in its effects. The type, intensity and result of participation in the social process of production dictates the definition, degree, evaluation of and attitude towards *normality* and *disability*. That this ultimately leads to stigmatization, isolation and segregation, I would like to illustrate for you in the following with the example of the institutions that are responsible for the care and welfare of the disabled. As I have already mentioned, North Africa is oriented to the individually based support, supervision and social integration of disabled persons, as fought for in Europe and as perceived here by the relevant organizations and associations. Without a doubt, this European development represents an important achievement in basic human rights and integration policy. People with disabilities have gained essential opportunities for action and freedoms of personal development. As a result, certain groups of disabled people, such as the blind and visually impaired, have been able to emancipate themselves. At the same time, however, they lived, and continue to live, in a *parallel society* during their schooling and vocational training and to an even greater extent later, when employed in their chosen occupations. They are certainly well protected and supported but, to a great extent, removed from the *normal* world. Thus, integration initially began with a well meaning but very problematic isolation that made the disabled person different from others. This is because the conceptual formation of the institutions designed to serve the needs of the disabled took place in a social order that was oriented to economic performance. As a result, the institutions themselves are not free of a certain definition monopoly in regard to *disability* and *normality*. Thus, the original good intentions fossilized into a patronizing attitude, social isolation and, finally, exclusion from a society determined more and more by productivity and performance. The labeling of this development as welfare despotism does not seem inappropriate.

In Germany, the forced incorporation into allegedly new structures, which is legitimated by economic arguments, naturally harbors a danger. This is that the disabled will once again be returned to a state of economic and social isolation. Since the current understanding of rights and responsibilities represents a unique instance, in the form an individualized and particularly compatible entitlement in relation to and through the state, the *liberated* disabled person has no communal and familial back-up system to rely on anymore. The disabled person is therefore confronted with three negative developments. The family no longer exists in the traditional sense; on the other hand, the access of the disabled to work and employment is increasingly limited; thirdly, the disabled themselves created, and continue to create, jobs in the care industry. The current health science and job market dimension of the debate totally objectifies disabled people. Therefore, can the manner of dealing with disability and the disabled, and the way that the disabled person is cared for within the Islamic community and family, point to a way out of the current dilemma?

A disenfranchisement of disabled people, such as we observe in Germany, does not occur in North African countries, as homes with residential care for the disabled hardly exist. In so far as they do exist, it is as part of educational facilities so that the stay of the disabled person in the institution is always temporary. In general, this means that the relationship between disabled and non-disabled people continues to be determined by traditional and religiously influenced structures in the North African countries. This, for example, hinders the exclusion of the disabled as well as that of elderly people. As a result, the North African societies are not focused, as are the European, on the image of the young and healthy person who is capable of high performance. Up to now, being different in these societies is not associated with social sanctions that ultimately lead to complete social isolation. Therefore, embeddedness and inclusion in the family and societal structures is a psycho-social and health-political necessity. The bonds to the family are expressed to a certain extent unconsciously in the form of actions that require no special reflection. In conclusion, we can say that there are essentially three differences between the situation of the disabled in Europe and in North Africa:

1. the definition, attitude, evaluation and way of dealing with disability and the disabled, originating in the communal- and family orientated tradition.
2. the social and political order, which is still largely rooted in the basic structure of the extended family.
3. the shared responsibility for the support and integration of disabled individuals resulting from this.

Of course, the situation of disabled people in terms of the job market in the North African countries is, as in Germany, generally characterized by disadvantage. This means that governmental support is also necessary there for the incorporation of disabled people into the work force. Nevertheless, the psycho-social situation of disabled people in North Africa is better than in Europe, as a consequence of the maintenance of traditional family relations. These intact North African family ties largely allow for the social integration of disabled members. For disabled immigrants, this means that the social and political situation in Germany cannot substitute for the experiences and fundamental familial and social ties that they brought with them.

NOTES

1 By North Africa the Maghreb states of Algeria, Tunisia, Morocco and Libya are meant.

2 The Sufi movement was founded in Baghdad in the 8th century. Sufism was basically a mystical movement that, among other things, opposed the civilizing tendencies of the ruling elite. Its members wore clothing made out of wool ("Suf" in Arabic) as an expression of purity and authenticity. They formed a community based on the form and style of the life of Mohammed. They developed, among other things, methods for the healing and treatment of illness. See Mustapha Ouertani 1993, p. 39.

3 On the politics of health care in North Africa after independence see, for the case of Tunisia Ouertani 1993, p. 39.

4 See Rolf G. Heinze: 1979, pp. 37–63. See also Thea Stroot, p. 9.

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THE PROBLEM OF *SPECIAL-EDUCATIONAL* ADVANCEMENT OF CHILDREN FROM MIGRANT FAMILIES – INTEGRATIVE HELP IN THE REGULAR SCHOOLS TO PREVENT MULTIPLE PROCESSES OF SOCIAL SEPARATION

Kerstin Merz-Atalik

CULTURALLY SPECIFIC INFLUENCES AS FACTORS AFFECTING ATTITUDES TOWARD ILLNESS AND DISABILITY

The theme of this volume is concepts and attitudes in relation to disability in different cultures. In the course of my many years of experience as an individual case- and family worker[1] involved in supervision of Turkish and Kurdish children with disabilities with the co-operation their families, I have noticed that differences in outlook, in terms of perception, evaluation and reaction to disability, have an influence on the concrete child rearing practices of parents. Such cultural factors also influence parents' acceptance of offers of non-familial parental counseling and therapy. When circumstances are unfavorable, such differences can lead to serious conflicts between professionals, institutions and families. The perception of and reaction to human *otherness* are subject to cultural influences. In the attitude towards and the social reaction to otherness (such as disability, cultural origin, abnormal behavior patterns etc.) we confront individual norms and values as well as those tending toward the universal. Neubert & Cloerkes (1994) differentiate, in their analyses of available ethnological studies for comparative purposes, the cross-cultural from the intra-cultural levels as well as attitude from the reactions to and behavioral responses to disabilities. They define disability, in this context, as "a way of being different that is generally evaluated as being very negative" (Cloerkes 1997: 100). On the basis of this they assume that, in the negative evaluation of disabilities, especially in the case of extreme deformity, culturally universal tendencies tend to prevail, whereas the patterns of active response to disabilities, in various cultures, tend rather to variation when seen from a cross-cultural perspective.

On the basis of my own experience as a social-pedagogical case and family worker, assisting families of German as well as of other cultural origins, and also reflecting on my co-operation with professionals in relation to this work, I can confirm that differentness[2] provokes similar reactions among people of various cultural backgrounds. Diverging from Cloerkes' assumption, I tend more to assume that the evaluation of this differentness is, in general, cross-culturally as well as intra-culturally variable. This may even be true on an inter-personal or even on the intra-subjective level. In my opinion even the values and norms which constitute the basis of the perceptions and evaluation of a disability are determined by various subjective and individual factors that are independent of membership in any national or territorial culture. A static concept of culture, based solely on territorial or national origin, must be critically examined in relation to social outlook and behavior. Such a concept is inadequate for the investigation of social behavior in terms of either cross-cultural or intra-cultural comparison and, in particular, seems totally unsuited for dealing with the phenomenon of *migration*. Thus, the existence of a nearly homogeneous *territorially defined, national culture of Germany at the present time can seriously be questioned* (irrespective of possible differences between the former East and West Germanies). Examined more closely, a growing *cultural heterogeneity* in the German population can be observed. One thinks, for example, of the increasing ethnic pluralization of the population through various waves of migration (labor migration, immigration from war and crisis zones, the opening of the European Common Market, etc.) and the pluralization of *life worlds* (stimulated by international tourism, the widening of horizons by the international media, the internationalization of the market etc). The migrant social network in Germany, especially, is characterized by a high degree of heterogeneity in cultural experiences and *life world* orientations. On the other hand, an Americanization can be widely observed that, with its *fitness philosophy*[3], is exercising considerable influence over the human image due to its strong norm and value orientation towards *youth, beauty and success*.

In relation to the intra-cultural level, Cloerkes supports the position that, in every culture, basic uniform attitudes towards disability predominate and that "socio-economic, demographic and personality specific variables are insignificant compared to extremely rigid attitudes" (Cloerkes 1997: 98). These influences should, in my opinion, be accorded a greater significance. On the basis of a wide range of experiences in working with migrants, I have come to the conclusion that sub-cultural and socio-cultural factors have a far greater influence on people's attitudes towards disability than their cultures of origin. Among Turkish and Kurdish migrant families, for example, I was able to establish that religious affiliation (as a cultural factor) had less of an influence on childrearing and educational plans for their disabled children than the socio-economic circumstances of their lives. The culture of origin, religious affiliation and the ethnicity of the individual families have been proved to have an influence on attitudes and behaviors towards people with disabilities (see Merz-Atalik 1997), even if these are highly individualized. Rather than the frequently used concept of *culturally specific attitudes*, in dealing with other cultures the *culturally specific influence factors* within the group and their individual expression in each case should be investigated. My experience confirms that we encounter, on the cross-cultural as well as on the intra-cultural level, a variability of attitudes and reactions to disabled people. In working with individuals and families of different cultural origins living in Germany, it is not sufficient to work with culturally bound categories. In order to understand the role of the reactions and attitudes of parents towards their disabled children, and thus also to be able to arrange training and education in special or integrated facilities, it is necessary to look into the individual ethnic and socio-cultural factors that are involved in each case (see Merz-Atalik 1998).

THE EXPERIENCE OF SOCIAL ISOLATION AND SEPARATION

> That racism and social racism go together and that we must take action against both is ... not obvious. (Sierck 1995: 6)

Tendencies to Isolation and Barriers to Action in the Parental Home

The overwhelming majority of families of pupils attending German schools who do not speak German as their first language, are of Kurdish or Turkish origin and come from Turkey. Turkey is a country which is characterized by a high degree of cultural heterogeneity and the Turkish population includes a variety of ethnic groups (Turks, Kurds, Arabs, Kyrgyz, Lazars etc.) and a number of religious groups (for example, Sunni, Alevite and other Muslims, Jews and Christians). In addition, the families who immigrated to Germany came from various, socio-economically very diverse, regions of Turkey (such as West, Central or Eastern Anatolia; from urban or rural areas). The coping mechanisms and the ways of interacting with a disabled child among families from Turkey are just as heterogeneous as their cultural backgrounds and patterns of living (see Skutta 1994). The individual and personal formation of the *life world* and the home life of Turkish and Kurdish families is dependent on numerous factors, for example on the reason for migration and when the family arrived in Germany (migrants of the first, second or third generation), the individual experience of migration, their socio-economic life circumstances, their educational level, religious affiliation and many other factors (see Merz-Atalik 1998).

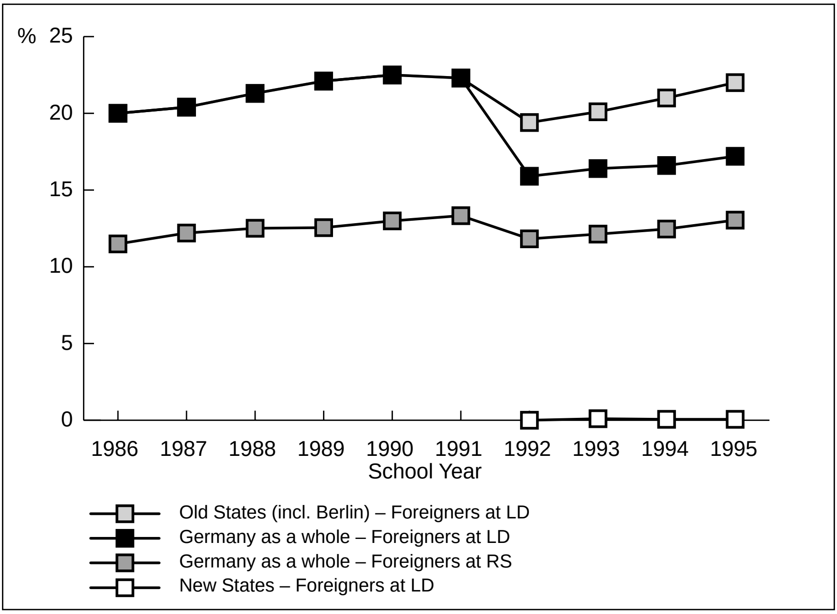
Schäfer-Böker (1987) researched the effects of a chronically ill or disabled child on the immigrant family system. She examined their coping mechanisms on the basis of case studies of twenty two immigrant families. As a result, she came to the conclusion that, contrary to her expectations, most families coped with the frustration resulting from their double burden (migration and caring for a disabled child) without taking the stress out on the child. To a much greater extent, the host society and the representatives of the medical system were the preferred targets of their aggressive impulses. "The parents believed, for example, that if they had not emigrated their child would not have become ill, since they frequently attributed the child's condition to malpractice on the part of German doctors" (Schäfer-Böker 1987: 97). The families appear, as a result of the double burden of *migration and a disabled child*, to have become closer and more supportive of each other. Separation of the parents was relatively infrequent. This is, in my estimation, generally true of Turkish and Kurdish families and not a specific phenomenon of families with disabled children. While Schäfer-Böker found an extremely high level of isolation among Turkish families with a chronically ill or disabled child, Hohmeir (1996) on the other hand contradicts the thesis of a high degree of isolation. The staff members of the early childhood development support centers whom he interviewed state that 76 percent of immigrant families receive help from relatives, but, with only 27 percent, they have contact with other families with disabled children to a lesser extent than German families. I found this to be the case for a majority of the families that I worked with. Most of their needs for social contact were taken care of within the family itself and their interaction with the social environment outside the extended family, for example with neighbors or co-workers, appeared to be limited. In my opinion, we can assume that this is also true for many Turkish and Kurdish migrant families without a disabled child. Relevant publications, discussions with primary and special education teachers and with a number of counseling services, suggest that parents frequently reject vigorously the assignment of their child to a special school for pupils with learning problems. In Turkey, a committed program of special education has only existed since the 1980s. In general, this involves special schools for the physically disabled (with organic impairments such as blindness, deafness and physical disabilities) that have been established for some time. In regard to these *physical disabilities* the acceptance of special education is still relatively high in comparison to that for attendance of a special school for children with learning or behavioral disorders (Boos-Nünning 1990).

Many Turkish and Kurdish parents are pleasantly surprised to learn about the possibility of schooling disabled pupils together with non-disabled children. This is especially true for parents who have non-disabled children already attending the school in question. The parents of non-disabled children have, however, the same reservations as many German parents and do not, in any case, want their children to be placed in the same classroom as *disabled* pupils. Many explanations have been offered for this behavior, which I do not wish to go into here. I see a major cause in the lack of information about opportunities for integrated schooling in Germany. Despite intensive inquiries for all the German federal states, I have not be able to find any specific information materials on the topic of *integrated schooling* designed for families of non-German origin. In my opinion, a direct translation of the language of information brochures is not suitable [4] (Merz-Atalik 1997).

School Tracking and Exclusion

As soon as their children start primary school, parents from the initial immigrant groups in post-war Germany, just like those coming from war and crisis zones, often have difficulties with the complex bureaucratic demands of the German educational system. These procedures tax the limited language skills of the immigrants as well as their ability to cope with complicated regulations. This is equally true for those schools that serve disabled children, including special schools as well as the various types of integrated educational alternatives. In some places, the decision to place a disabled child in a regular school together with non-disabled children demands high levels of commitment and persistence on the part of parents (for example, in the German states where special schools for disabled pupils are the rule and mainstreaming of disabled children in regular schools is the exception). In the special schools, and especially in the schools for children with learning disabilities and mental retardation, a significant over-representation of children who speak languages other than German as their first language has been observed. Since the 1970s, the proportion of immigrant children[5], placed in schools for the mentally retarded increased from approximately 0.5 percent to 23.9 percent (1993) (Kornmann and Klingele 1996, 1997).

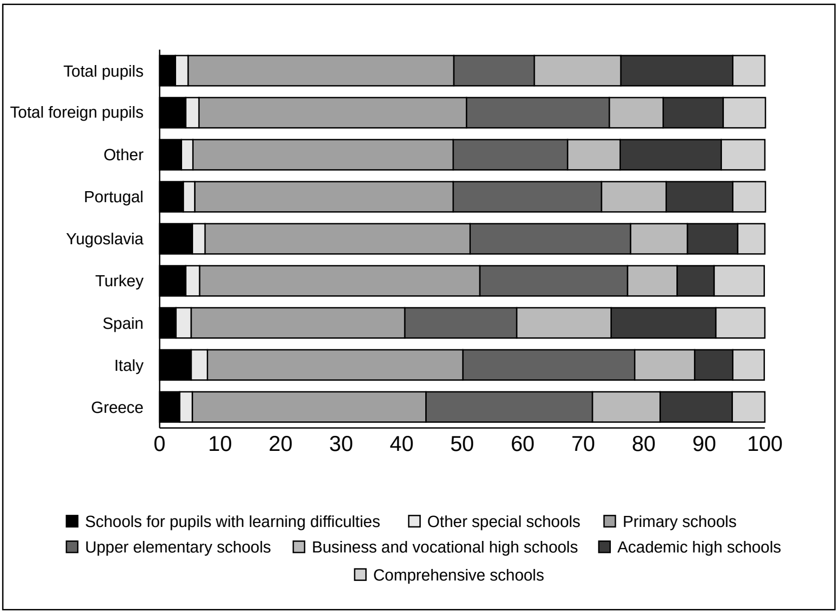
Table 1: Comparison of the growth of the number of children of immigrant parents attending schools for the learning disabled (LD) with that of those attending regular schools (RS) (in Germany as whole)



(Calculations based on: Secretariat of the Standing Conference of Ministries of Education of the States of the German Federal Republic (ed.). *Foreign Pupils and School Graduates 1986-1995.* Statistical Publications of the Education Ministries Conference, no. 138, December 1996).

At this point, one might say that the causes of disturbances in the social and learning behavior of the children of migrants, such as language and cultural barriers, are known (for example, see UCAR 1996) and have been taken into consideration for years in the discussion on cross-cultural teaching (Auernheimer 1990). In contrast to the usual assumptions, it is not just the children of recent migrant families that are over-represented in the special schools but even children coming from families of the so-called second and third generations (for example the children of Italian immigrants).

Table 2: Distribution of pupils of various national origins in the general education schools in the school year 1996 (for Germany as whole)



(Calculations based on: Secretariat of the Standing Conference of Ministries of Education of the States of the Federal German Republic (ed.). Foreign Pupils and School Graduates 1986-1995. Statistical Publications of the Education Ministries Conference, no. 143, December 1997).

The diagram shows clearly that pupils of foreign national origin more frequently attend schools for pupils with learning difficulties and the mentally retarded than is characteristic for German school attenders as a whole. This is obviously true for the group of pupils coming from the countries that were formerly part of Yugoslavia and from Italy. In terms of secondary education, it can be established that a far larger proportion of the children of immigrants are assigned to the vocationally-oriented *Hauptschulen* (upper elementary schools). Only pupils from the *other* country of origin group and from Spain indicate a rate of attendance at the *Gymnasien* (academic high schools) that is comparable with that of pupils in the German schools as a whole. From the perspective of the educational sciences, the causes of this situation are seen, in particular, as being the selective structures of the German school system and educational planning which is oriented to the typical German middle class family. Children with socio-cultural life circumstances that diverge from this statistical norm are systematically disadvantaged. Especially in terms of attendance of schools for the learning disabled, but also for all other special schools, we can show that the children of migrants are over represented. In the case of Denmark, Jabiri and Kruuse (1992) come to the conclusion that migrant families have a greater chance of having a disabled child. Their explanation for this higher risk is, among other factors, the primitive conditions associated with childbirth which prevail in the migrants' home countries. Turkish and Kurdish families more often have disabled children as a result of marriages between close relatives, such as between cousins. Many families with disabled children also deliberately migrate, or abandon plans to return home, because of the better medical and therapeutic care available in the host country (see Merz-Atalik 1997).

A few years ago, it was assumed that the over-representation of children of immigrants in special schools would be reduced with the increasing length of residence of their families in Germany. Today we must admit that this has not happened (see initial immigrant groups in table 2). The proportion of children of immigrant families attending schools for the pupils with learning difficulties and the mentally retarded continues to increase. As a result of continuing immigration from war and crisis zones the (special) school is confronted with cultural heterogeneity among the group of children that it serves and is being challenged to adjust its basic organizational structures, curriculum and teaching methods to the increasingly multi-cultural nature of German society. The processes of educational sorting and separation into groups also occurs within the classroom itself and can lead to a marginalization of children of non-German origin. Doris Houbé-Müller discovered, by means of a qualitative analysis of social conditions of marginalized immigrant children in school classes, that "in reference to peer relations, three out of five immigrant children attribute their marginalized position to their status as foreigners" (Houbé-Müller 1996: 233).

OPPORTUNITIES FOR INTEGRATION SUPPORT

As the conditions presented above show, disabled children from cultural and ethnic minorities, and their families, are increasingly threatened by risks of social isolation and separation. This can be demonstrated especially in the case of institutionalized offers of counseling, assistance in childrearing and schooling for children with disabilities. These increased risks can be identified or suspected on all levels of the *integrative process* (Reiser 1990). Examples of such risks are experiences of persecution, war or being a refugee as influential factors on the global level, life as a member of a cultural minority on the societal level and the tracking practices of the German school system, as suggested above, on the institutional level. On the situational-environmental level, deviations in the *life world* experiences of migrants make integration into the existing system difficult, when such differences conflict with German expectations of cultural homogeneity. On the level of classroom teaching, this is especially true in regard to educational materials. These are mono-cultural in content and approach. On the psychological level, one can imagine that this could have a negative effect on the self-esteem of children of non-German origin (see Houbé-Müller). Language and cultural barriers interfere with integration on the social interaction level.

The challenge of cross-cultural lesson content and instruction lies in adequately dealing with the cultural and language heterogeneity of specific groups of pupils.

> This should ... not be carried out by means of the old, segregative, methods. It should be accomplished without pressure for conformity and without threats of division of the group, on the basis of selective criteria, in response to cultural and language differences. (Hinz 1993: 225)

These calls for educational methods and contents appropriate for culturally heterogeneous groups are also central to the basic ideas about teaching children with disabilities together with non-disabled children in the same classroom. The goal is to create a learning and teaching culture in which all children can feel secure and cared for. At school, children must be able to have the experience that, instead of being branded for their weaknesses, they are supported in developing their strengths.

> Here the opportunities connected with mainstreaming in the classroom clearly reveal themselves: we mean, living with human variety, seeing difference as a positive and enriching stimulus, recognizing the individuality of the other as unique, but also productively dealing

> with the conflicts that arise from heterogeneity and making and keeping rules for getting along. (Werning 1996: 468)

Werning sees the pedagogical-didactic challenges of this kind of teaching as:
- the perception and taking into consideration of the *life world* of the pupil,
- stimulating, supporting and supervising the development of social resources through common action characterized by solidarity,
- overcoming a deficit orientation in favor of one focused on abilities,
- accomplishing these goals through collegial co-operation.

In doing so we are no longer emphasizing whether, for example, we are concerned with heterogeneity in capabilities, giftedness, gender or *life worlds*. Proceeding from the basic idea of the *contact hypothesis* (Cloerkes 1997), that an intensive, protracted and encompassing contact with human otherness can lead to positive changes in outlook, difference at school should be accepted and be interpreted as an exciting expression of human variety.

NOTES

1 In connection with the individual integration of children and youth with disabilities or impairments into various areas of social life (such as day care centers, schools, employment, recreation and housing), for over fifteen years individual case workers in Berlin have been employed and funded within the framework of social integration assistance measures mandated by German Federal Social Welfare legislation.

2 In contrast to the term *otherness*, as used by Cloerkes (1997), I use the term *differentness* here. People with disabilities are in no way *other* but are disabled by a specific characteristic that affects their social existence.

3 See Udo Sierck: Integration and the Fitness Philosophy. Paper presented at the Conference for Integration Research, Hamburg, Germany: February 21–24, 1996.

4 My letters to the state task forces of the German Association *Living Together and Learning Together e. V.* in March 1995, requesting information materials or brochures on the school integration of disabled with non-disabled children for non-German (especially Turkish and Kurdish) parents, all received negative replies.

5 Author's comment: A basic limitation is noted for studies that deal with immigrants in Germany as a single group. The results obtained by means of this approach ignore the variety of life experience and backgrounds of the *foreign* population in Germany and, thus, are of limited validity.

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DISABILITY AND KNOWLEDGE TRANSFER IN THE FIELD OF DEVELOPMENT COOPERATION

LOCAL KNOWLEDGE AND INTERNATIONAL COLLABORATION IN DISABILITY PROGRAMS

Patrick J. Devlieger

Disability is a sensitive barometer for local development. How people with disabilities fare immediately reflects their culture. In our global times of information exchange, political, economical and social interdependence, the discourse of disability is constantly taking new turns, primarily based on an ideology of human rights, geared towards community based activities, and support rather than service. In local contexts, the communication and implementation of these ideas have been very varied. In this variation, local knowledge of disability proves to be very resilient. In the past few decades, policy makers and professionals in the South have learnt the international language of bilateral, multilateral, and service development standards imposed by international and national non-governmental organizations. Some of the initiatives resulting from the new language have had tangible outcomes for the lives of disabled people and their families, but others failed to reach out, sometimes due to the intentions of planners, sometimes because of the way international collaboration works in the negotiation and allocation of funds, asymmetrical and inefficient interaction and implementation, and lack of understanding of local knowledge and priorities. In this article, global and local knowledge are considered to be two sides of the coin of disability knowledge. They are considered to be more or less independent developments; one may have developed in capital cities around the world, the other in the course of the history and culture of communities. Yet, in an interdependent world and in the way they become real behavior and initiatives of or for people with disabilities, they become mutually constitutive. For example, the liberation war of Zimbabwe produced a language of liberation and ultimately a new government but also a great number of disabled veterans who created home-grown potential for local cultural change. The language of human rights for disabled people coincided fairly well with this potential and accounts for the leadership Zimbabwe has shown in mounting a disability movement, both locally and globally. The purpose of this article is to explore the two sides of disability knowledge and in particular to explore the importance of local knowledge for international collaboration.

What is global knowledge of disability? In an interdependent world of international relationships and organizations, global knowledge is a layer of standards to which countries and regions refer as they evaluate themselves and each other and seek direction for new development. Global knowledge is developed across cultural and national boundaries. It first becomes reflected in policy statements and new initiatives. Global knowledge creates tensions with what is already known, what is homegrown in languages, cultures, and history. The global discourse of human rights has supported the worldwide recognition of disabled people and provided the foundation for a worldwide movement. Disabled people in many countries, both in the North and the South, have found that it is good to organize themselves. The commonality of disability speaks loud and clear beyond the differences of gender, race, culture, and professional background because the agenda seems quite clear: better lives. Global knowledge is knowledge that easily survives in conferences, policies, and legislation. It becomes local if it survives the stage of reflection and conceptualization and permeates culture and history. Local knowledge of disability is cast in the daily relationships between disabled and able-bodied individuals. It is found in the particulars of languages and cultural capital; in the history of the emergence and disappearance of disabilities; in the social, political, racial, sexual, and ecological environments of individuals; and in the very history of services and supports for disabled people as reflected by the moral and political relationships between a society and its members with disabilities. Local knowledge is not static because cultures and societies are not static; culture is built and built upon (cf. Whyte/Ingstad 1998).

New developments of international interdependence and current understanding of international disability work may lead to a new orientation. Countries in the North and the South are starting to frame their relationships differently. The power relationships of colonialism and post-colonialism have altered in a post-cold war era to make way for more interdependence. This partly emerges from the realization that questions of economic development and international security cannot be solved in a vacuum. Interdependence is also supported by the global market and information industries. The need for local knowledge in order to be effective, and an understanding of the world as interdependent, seem to be the two sides of the coin that may lead to more effective and culturally sensitive work in disability programs. In order to explore the tension between the local and the global, I will first discuss how a new global context may inform international disability collaboration. Then, I will discuss how local cultural, historical, and technological knowledge of disability may be generated and may interplay with global knowledge. My views on these questions are informed by research in African countries, my participation in disability programs run by non-governmental organizations and the United Nations, and my current involvement in the development of disability studies in the United States.

THE VOICE OF DISABLED PEOPLE AND THE POSSIBILITY OF INTERNATIONAL EXCHANGE

The fact that people with disabilities have been organizing themselves in formal organizations and informal networks, both in the North and the South, has developed a new level of consciousness that permeates the way governments, non-governmental organizations, and universities can engage in the *disability business*. The sensitivities of disabled people themselves, as they relate to the cultural understanding of disability, the issue of discrimination, and the services in education, employment, and health care have therefore a greater chance of being included in the knowledge base. Listening to disabled people as part of the planning and implementation process of disability programs seems like a common sense issue. However, much of the international collaboration has failed to see the benefit of including people with disabilities in planning and designing programs. The voice of disabled people is fundamental to the understanding of disability itself. Disabled people have the experience of living in families, communities, and society, and a vision of disability and disability programs must develop in the interaction between disabled and able-bodied people. Both are part of the equation. This principle is now being tried out in some universities in the North. After developing an academic home for cultural minority populations and women, first attempts are now being made at developing training and research programs in disability studies. These programs are based on interdisciplinary collaboration and actively involve people with disabilities as leaders and partners in training and research. This new development will have international ripple effects that extend to international work and disability programs in the South. Enhancing the voice of disabled people in an international context may be facilitated by global developments. First, the organization of international travel, the information networks, and potential of new technological developments in communication make it possible for people with disabilities to be involved more significantly. More important, in the context of North-South relationships, it may also mean that the potential of mutual development between the North and South in the area of disability may be enhanced. The breakdown of old power relationships and the acceleration of exchange have increased the vulnerability of countries in the North. This could mean that the export of development by Northern countries is replaced by mutual development, i.e. collaboration needs to work both ways, and a mode of interdependence is developed. In concrete terms, one may expect that disability program development worldwide may benefit from this development.

Collaborative program development in a global perspective may therefore have the following characteristics. A global discourse on disability will continue to develop. International definitions and standards will remain guidelines on policy and service for organizations and governments. However, the local contexts of countries, including historically, culturally, and technologically situated understandings of disability and economic conditions, will constantly threaten the usefulness and validity of international definitions and standards. More promising is the collaboration between organizations, governments, and universities that examine strategies of mutual development. Program development in the North may benefit developments in the South, but equally now, the reverse needs to be made possible. A number of organizations in the North are starting to develop these strategies. Last but not least, the involvement of individuals with disabilities every step of the way, in program and research design and development, is a matter of principle.

GENERATING LOCAL KNOWLEDGE: THE POWER OF LANGUAGE, HISTORY, AND TECHNOLOGY

Advocating new ways of collaborating assumes that the knowledge base for such collaboration is readily available. This is unfortunately not the case. Only in recent times have initial conscious efforts been undertaken toward systematic research into social and cultural understandings of disability in the contexts of countries of the South (for an overview, see Ingstad/Whyte 1995). Belief systems pertaining to the causality of disability as part of the more global understanding of cosmologies and the implications for care and service have received some attention. Many questions remain. For example: Does this information suffice as a knowledge base for international collaboration? Is this information legitimately produced? What other types of information need to be generated and who needs to be involved?

In the context of mutual development and intercultural understanding, I would like to stress three types of knowledge that constitute the premise for a knowledge base: language use, technology and the history of disability. I emphasize these types of knowledge because of their potential for an impetus for change and development that may indeed result in the improvement of lives of people with disabilities. A cross-cultural understanding of disability is hampered at the outset by a conceptual and a language problem. What is understood by *disability* in countries in the North is informed by cultural differences and historical backgrounds. For example, the idea of disability as a major concept of discourse in the United States is informed by conceptual developments that move away from the term *handicap* and by legal developments, the most important being the Americans with Disabilities Act of 1990, which situate the problem of disability in the environment rather than in the individual with a disability (Devlieger 1997). The concept of handicap or disability as one that is applied to a vast variety of people with many different impairments is one that has been exported from the North to the South and popularized by United Nations initiatives. Yet it remains a concept that is difficult to define in global terms because it means something different for every person so labeled and for people with different cultural backgrounds. This messiness is an invitation to enhance the importance of society and culture in the understanding of disability. There are ways out of the messiness of disability, paradoxically by bringing it to the forefront. In producing and using the knowledge that underlines the complexity of disability in its cultural context, the way may also be paved toward greater cultural sensitivity and efficiency.

Local knowledge of disability is captured in the language of people. This is a vast area that has mostly been ignored in the history of collaboration. Colonial officers, missionaries, government, and development workers have often placed disability on the agenda without finding out what people already knew. They did not see that such information might be available or believed that it would be too hard to obtain or else the colonial language situation simply prevented the exploration of such knowledge. In any event, information in local languages that relates to disability includes the particular terminologies that designate people with disabilities, proverbial language that directly speaks to people with disabilities or uses disability as a metaphor for other situations and fables that include characters who challenge incompetence or limitations. This knowledge was developed over a considerable time and is as old as culture itself. For most people with a disability, it is this knowledge that informs who they are as disabled individuals, i.e., what is expected of them, and how they are valued. There are many possible ways of working with this cultural material. Listening to disabled people and to people in families and communities may quickly yield cultural information captured in indigenous narrative and discourse. A more important challenge, however, lies perhaps in the cultural production of this material. An interesting example of this occurred in Tanzania, where blind people rejected the term *kipofu*, because of negative connotations (Kisanji, personal communication). In the Swahili grammatical structure, *kipofu* is classified among terms that do not usually designate a human category. By requesting that they called be called msiona (plural wasiona), blind people defined themselves in the human category, simply as "the one that does not see". The struggle over terminology designation is not simply a matter of esthetics. It is a political and cultural process that determines how societies relate to their members who are disabled. Engaging in this process may not only clarify important issues that remain under the surface, it may also have important policy and legal implications. Terminology, proverbial language, and fables are the cultural language capital relating to disability in countries in the South. International collaboration has not worked in favor of exploring this information, but rather efforts have been devoted to assuming the various aspects of discourse of the North. The impact of efforts that bring out this information, in the form of research publications and training material, should not be underestimated.

A second proposal that I would like to advance is work on the cultural history of disability in the South. To date, for example, there is very little documentation on the cultural history of disabled people in countries of the South (e.g. Devlieger 1995; Iliffe 1987). Yet to know who you are as a disabled individual is to know where you come from in terms of the history of disability treatment. In the production of this local knowledge, individuals with disabilities, together with their families and communities, need to play extraordinary roles. The social sciences and the humanities departments at universities in the North and South need to take up the responsibility for these tasks. Technology is another very localized knowledge that can perhaps be best examined in an example. In a medical development project in central Zaire, a team of expatriate doctors, missionaries, and the local Catholic church embarked on a project that was nurtured by the spirit of the International Year of Disabled People, by Christian values of justice and the role of the church in development, and by Western ideas of social development. The core of the program focused on surgical operations on children with lower limb deformations resulting from polio, medical rehabilitation that focused on fitting the children with plaster to stabilize the corrective surgery, followed by fitting primitive braces and crutches, produced by local technicians, and instructive physical therapy with its emphasis on the ability to walk. Noble as it was, the project showed many flaws, one of which was the neglect of existing technology. Children and their parents who live off the products of nature in the Kasai region of Congo have become inventive with solutions, in spite of a low level of technology. The standard cultural solution for a deficiency in walking, especially when due to a lack of strength in one of the legs, is to simply cut a stick from a tree that is fit for the weight and length of the individual. The stick is used as a support for the transfer of the weight in walking. This is an ancient method that was also found in ancient Egyptian civilizations, as we know from depictions (see Paul 1971). As it turned out, the stick proved superior to the braces. Local knowledge that surrounded the rehabilitation proved very resilient. First, it was expected from the rehabilitation that a deficient leg was going to regain its strength. Much hope was invested in the white plaster as a substance that would strengthen and would help regain force. Patients after surgery had to wear the plaster for several weeks. When the plaster was removed, some disappointment evolved. The patients were under anesthesia for the operation and had not seen their leg for several weeks. Now that the plaster was removed they discovered that despite the surgery and the plaster the leg was still not *healed*. The same disappointment was extended, but in a lesser degree, with the fitting of the braces. One family stated, at the end of the rehabilitation period, that they would hold off with a big party of celebration until the braces could be taken off after strength in the leg was fully regained. These medical rehabilitation technologies that were meant to stabilize a leg were unable to meet the cultural demand of the Songye and Luba people of the Kasai region to regain strength. Over a period of time, I observed with a number of persons that the braces had been abandoned and replaced by yet another new stick. The reasons were that the braces and crutches needed to be adapted or replaced over time (since children tend to grow!) and the facilities for adapting them may have been too far away, too costly, or too inefficient. While most materials could be obtained locally, such as wood, leather, and iron bars, the supply could be irregular. On the other hand, a stick that matched the length and weight of the individual could easily be cut from a tree at no cost and sufficiently provided the support needed while not leading to culturally informed disappointment. While it did not free the hands while walking as did the braces, this advantage did in general not seem to be crucial. It would have been crucial if the braces could have provided the balance necessary for women to carry loads on their heads as this is a culturally normative expectation. However, the braces, primitive as they were, could not match the superiority of balance that is possible with barefoot walking.

Local knowledge is cultural, historical, and technological. As sources of identity and pride, it also indicates directions for future development. The exchange of such historical knowledge between countries of the North and the South does not need to be unidirectional. Creating cultural and historical knowledge may prevent disability from being dealt with in a vacuum. What does seem to be crucial is the production of knowledge where local and global developments can meet, an intermediary discourse. The non-governmental organizations as the major implementors of development activities and the universities as producers of knowledge have had awkward relationships that sometimes lead to productive results but also stumble over differences in agendas and time perspectives. An evaluation of this relationship seems necessary and the only promise of the development of local and intermediary discourses.

CONCLUSION

Here, I have considered the new global context of international disability collaboration and the role of local knowledge. We can now answer the question, "Is cultural sensitivity possible in international disability work?" The answer is complex and will need to evolve in the practical forms of collaboration; but some directions seem to be emerging. I have furthermore considered two aspects of local knowledge production. First, listen to disabled people, at the very least. Much better even is to place disabled people in central positions of design and implementation. Local knowledge production as it emerges from the interaction of disabled and able-bodied people has the potential to be more genuine, rich, and practical. Second, collaboration has to be a two-way process. For the North it means an openness to welcome the South as a partner in the development processes of the North. For the South it means a responsibility to document local knowledge of disability that can be built upon and to make the North a partner in the process. Bilateral exchanges between peoples of the north, the development of sister organizations. In particular, the universities of the North and the South have important responsibilities and opportunities of collaboration. Finally, globalization processes stimulate the development of interdependence in ways that could not be imagined until recently. For people with disabilities and international collaboration, this means a potential for enablement and mutual understanding. Unfortunately, it may also mean new layers of discourse and discrimination that shift cultural understanding of ability and competence once again. Within these global developments, the challenge will remain to keep in tune with local processes. In meeting this challenge, disability remains a sensitive barometer.

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POSSIBILITIES FOR WORKING WITH CULTURAL KNOWLEDGE IN THE REHABILITATION OF MINE VICTIMS IN LUENA, ANGOLA

Ulrich Tietze

INTRODUCTION

Following the signing of a peace treaty by the parties fighting the civil war in November, 1994 in Lusaka, there arose justifiable hope that the civil war in Angola was finally over. The war had lasted for over twenty years and had cost thousands of human lives. Tens of thousands were left injured and mutilated. Above all, the land mines used by both sides had cost countless people their limbs or their eyesight. This was true for soldiers but even more for the civilian population. In order to relieve the suffering of the victims of the war and mine injuries, at the end of 1995 Medico International, the Frankfurt-based aid organization for social medicine, began building a center for community-oriented rehabilitation. Together with my colleague Ralf Syring, I organized the setting up of the center and headed it during the first two years of its operation. During this time, I was confronted with a wide range of problems that are frequently too trivial in nature to talk about in detail. Taken as a whole, however, they constitute a part of the culturally specific information that determines the greatest portion of our practical work on a day to day basis. Perhaps these things should not even be mentioned in this article. But who would suspect that such simple things as the qualities of water, light, fuel, the wood used for building houses, or a few nails would make up a substantial part of the project activities of the rehabilitation center? *Culturally specific information* is commonly understood in a different way. Nevertheless, the greater part of Angola, and with it also the majority of the people who live there, is characterized by the culture of a post-war society. This post-war Angolan society is marked more by a culture of scarcity than by traditional, independent, cultural elements.

When describing *Disability in Different Cultures* we should not forget that many of the countries of the Third World, and especially Africa, are still in a state of war or in a post-war condition. An additional fact is that not only the disabilities of the people in these countries, but also the problems that arise in the course of their treatment and rehabilitation, have their origins in the typical features of a post-war society. Thus, it seems legitimate to me to use the concept of *culturally specific information* in my account differently than it is normally used.

MEDICO IN ANGOLA

For several years Medico International has been involved in the treatment of disabled people in a number of countries of the Third World. Having started with support for a workshop manufacturing artificial limbs in El Salvador and a rehabilitation center in Cambodia, in 1995 Medico intensified its work in Angola. We chose Luena, the capitol of Moxico, the most eastern province of Angola, as the location for a center for community-oriented rehabilitation. Luena is a city with approximately 80,000 inhabitants. In former times the economic life of the city was centered around the Benguela Railroad, which connected the copper producing region of Zambia and the former Zaire with the Angolan port of Lobito. During the last years of the civil war, which raged most fiercely between the first Peace Agreement of 1992 and the last in 1994, an additional 80,000 people fled to Luena from throughout the entire province. The countryside surrounding the city was mined several times, partly to prevent attacking armies from entering the city, partly to prevent the city's inhabitants from leaving. The mine belt was so dense that, for years, the city could only be supplied from the air and the first truck convoy only reached the city in October 1996, after Luena had been cut off from the outside world for over four years.

Proceeding on the basis of experience in other countries, where we had been confronted in various ways with the rehabilitation of mine victims, we developed an exemplary plan to provide comprehensive assistance for these people in all areas of life. This plan was also reflected later in the guidelines of the anti-mine program of the German Action Group for the Banning of Land Mines. It had been clear to us for a long time that the people who had lost a leg through a mine explosion were not helped by only being fitted with an artificial limb. We knew, for example, that efforts to help the victims of land mines would only be credible if, at the same time, the mine fields were cleared, since accidents were constantly occurring. Part of our project, as a result, involved close co-operation with the British Mines Advisory Group, which was engaged in land mine removal in this region of Angola. We also knew that the victims of mine-related accidents needed immediate medical treatment to reduce their risks of dying from loss of blood or as the result of infected wounds. And we had to think about the provision of temporary aids to mobility, such as crutches and wheel chairs, that would enable the injured persons to get around until they actually received their new leg and were able to walk with it. As a result, support for the local hospital and the distribution of crutches or wheel chairs was one of our first activities. In co-operation with the Vietnam Veterans of America Foundation, we were able to set up a workshop that started producing the first lower leg prostheses in October, 1997. This workshop for the production of artificial limbs has an attached physiotherapy department. Residential accommodation for patients who come from distant rural areas completes this facility. Even this was not enough. A former patient in Cambodia, whom we encountered begging on the side of the road, answered our question of why he was not wearing his new prosthesis very clearly. "Your new leg doesn't feed my stomach!" This answer reveals, in its precision, a central problem of *cultural knowledge* in relation to work with disabled people in developing countries. The restoration of the physical form and function of the disabled person was not an adequate goal for the project. More basic and ongoing measures were necessary to improve the lot of the disabled in a society so torn by war and the expulsion of people from their local areas.

1. Disabled persons must have the possibility of earning a living and of supporting themselves and their families.
2. The network of social ties within the family and the community, which allows for reciprocal help and support for the disabled, must be regenerated.
3. Communication among the members of the village community disrupted (or destroyed) by the effects of war and forced population movements must be stabilized and contact among members improved before community-oriented rehabilitation measures can even be attempted.

This is where our understanding of psycho-social work with the disabled comes into play: the attempt to revive the self confidence of the disabled person, along with that of the village community, also strengthens the sense of personal initiative and willingness to accept responsibility among the people.

THE SITUATION OF DISABLED PEOPLE IN ANGOLA AND THE ROLE OF THE ORGANIZATIONS ACTING ON THEIR BEHALF

According to the official statement of the Angolan Ministry for Health, there are approximately 100,000 disabled people in the country today. According to an independent study in 1989, 73 percent of physically disabled persons in Angola had had one or more limbs amputated. Moxico was named as being among the provinces of Angola with the highest concentrations of amputees. However, there is no official estimate of the total number of physically disabled people in the province at the present time. Approximately 3,300 people are currently registered as physically disabled in Luena. Reliable estimates assume that about 1,500 of these have suffered leg amputations.

As early as Summer 1995, Medico was in contact with ANDA. ANDA is the national organization for disabled people which was established as an NGO by military and civilian disabled people to represent their interests. The organization's regional representative in Luena particularly impressed us with his detailed knowledge. He expressed a great deal of interest in our integrated approach and especially emphasized the large numbers of disabled. In the meantime it has become apparent that the role of ANDA, and particularly that of its provincial staff members, can be best described as that of *professional beggar*. Their relations over the years with NGOs and United Nations organizations had made the group so pliant in their rhetoric that, after a few sentences, you noticed which approach to aid was being advocated by whichever national or international organizations that they were dealing with at the time. They were able to adapt to any discussion partner in a chameleon-like way. One of ANDA's few accomplishments was the keeping of an indexed file of their clients. This list served as a source of data for practically all of the national and international aid organizations and thus served, in an essential way, to enable the distributers of food rations to organize their operations. Because disabled persons, like orphans and refugees, belong to the especially needy groups, the people on this list receive an extra ration of free food. Therefore, it is not surprising that places on this list were openly bought and sold. This too is a culturally specific problem of a special kind.

On the other hand, it was entirely possible to co-operate effectively with some individual members of this organization. However, they had to first learn how to approach their own clientele again, step by step. They had become much too accustomed to operating according to a bureaucratic administrator mentality, and evaluated their work in terms of an impressive office and a swollen organizational structure. The core of our own file of physically disabled persons in Luena and its hinterland was compiled by a few members of ANDA. In the process, it was revealed that often the functionaries of the organization were visiting other disabled people at home for the first time and finally witnessing the terrible suffering of their clients face to face. This was an extremely helpful experience for people who, for years, had been accustomed to graphically describing the terrible suffering of their members to foreign aid workers. Today, the file contains information about approximately 900 physically disabled persons, including 518 mine victims.

THE TARGET GROUP

With the first attempts to develop a program of assistance for the core of our target group, the disabled victims of war and land mines, it soon became apparent that the European-oriented approach to the social reintegration of the disabled in many cases was not suitable for the actual situation. This was because, when we observed the condition of the *non*-disabled more carefully, in many ways it was not essentially very different from the situation of the disabled. As refugees, the members of both groups have no opportunity to support themselves economically and they are, temporarily at least, dependent on outside assistance. As settled residents of the city, both groups are forced to earn a meager income though petty trade at the marketplace or through the illegal distillation of liquor. Both groups have little opportunity to receive adequate health care or schooling. This is a phenomenon that is readily overlooked in investigations into the condition of disabled people when interest is too exclusively focused on the disabled themselves (Ingstad 1997: 20). We sometimes observed exactly the opposite. Often the disabled appeared to be essentially more demanding than the rest of the poor population, although they were already the beneficiaries of free food rations. Above all, former soldiers are very skillful, often playing the moralistic card very aggressively, at putting the representatives of aid organizations in uncomfortable situations when they stop the foreigners' cars on the street to beg or to demand a lift. Along with this, we observe over and over in daily life that the people of the city hardly make a distinction between the injured and the non-injured. The woman on crutches with a baby on her back, carrying a basket of dried fish on her head to the marketplace, hardly evokes any extra sympathy in Luena.

The customers haggle over her prices just as vigorously as over those of the other fish sellers at the market. We also could not establish that any special consideration was being extended to disabled people, at least to those who were among the less severely disabled. Even the driver employed in our project, from whom one might expect a certain degree of sensitivity, would honk the horn loudly if someone was crossing the street too slowly. It did not matter if the pedestrian was walking with crutches or on two legs.

CULTURAL KNOWLEDGE, HOW CAN WE OBTAIN IT?

Besides this culturally specific information, which can be observed to arise directly from the culture of poverty and the results of war, there are still other aspects which play a role. These additional aspects result from traditional ideas, reservations based on experience or other cultural elements, and other information that is possible to obtain and which could certainly influence the work of the project. Thus, the obligatory question arises of how can we gain this information. Cultural knowledge can only be applied to some aspect of the project's work if it is available. In the initial phase of its community-oriented rehabilitation project in eastern Angola, Medico International made the attempt to learn something about the situation of those people whose needs were supposed to constitute the focus of the project. In order to do this, we applied the classic method for gathering data. We selected a group of eight women and men from the region to work with. All of these eight people had attended school for a minimum eight years and some had as much as twelve years of education. In personal interviews all of the eight had fulfilled our expectations of people who do not want to teach other people something but, rather, were open to learning something through contact with others. They also had to pass a written test. This written test was so structured as to indicate to us which persons were sufficiently prepared to listen carefully to informants' statements and to record these statements. The test indicated if the candidate was capable of listening in a nonjudgemental way to the expression of attitudes that might contradict their own. In addition, an important criterion was knowledge of the major languages spoken in the region.

CLASSIC DATA COLLECTION IN A CULTURE OF POVERTY

In co-operation with an experienced Angolan social worker from Luanda, we carried out an introductory course in our desired methods of gathering information with the eight people that we had chosen. Already at this stage, we were taking numerous steps that had to with culturally specific factors although we had very little cultural information available to work with at this point. From those people chosen to carry out the data collection, we encountered no disagreement. They all wanted to work for a foreign NGO, even if it was only for a short period of time, and hoped to improve their income as a result. Most of them had taken leave from their jobs with the government to be able to work for us. In their regular employment they received very low pay and were paid, at the most, every few months. This wish to improve, through us, their material circumstances overlay everything that we did from that point on. The extent of the influence of this specific aspect of a culture of poverty only became clear to us in the course of our work.

THE ATTEMPT TO CONSTRUCT AN OPEN-ENDED INSTRUMENT OF DATA COLLECTION

We wanted to prepare our eight new employees to administer a data collection instrument which consisted of several components. Firstly, there was a standardized part: a questionnaire that was intended to gather some personal data and also data about the type of disability. We especially needed, for the production of artificial limbs, information about possible amputations, about crutches and wheelchairs already in use, the wearing or not of shoes etc. Next came a semi-standardized section: using an outline, at least two persons would gather information by means of an interview. During the interview, notes were not to be taken. As much as possible, the details of the interview should be retained in the memories of the interviewers and, immediately afterwards, be recorded as exactly as possible. In this way, we tried to insure that as little as possible interpretation and summarizing occurred. What this was supposed to achieve, we attempted to explain with the following example, among others. An ill person arrives at a medical station and tells the nurse, "I have a cat in my belly." The nurse translates for the doctor, "She says she has stomach pains." Thus, the doctor cannot know what the expression "cat in my belly" reveals about the quality of the pain. Our original intention to develop the outline for the interview together with the Angolans was not successful. Over and over, they asked us to state our questions and then they agreed to these questions. We wanted to know what it means for a person to be disabled in every zone of the eastern part of Angola, what the non-disabled inhabitants of a village or residential district in the city think about the disabled, and how disabled people are dealt with and treated. While doing this, it was very clear to us that our own views of the disabled, and their position in society, would be reflected in the data collection process. However, we believed that this bias would be reduced and modified if people from the region, speaking the same language as the villagers, were collecting the information.

DISABILITY AND ITS CAUSES

Eventually, the protocols of interviews with two hundred disabled persons and seventy five family members lay before us. The final evaluation has, up to now, proved to be more work than we anticipated and still remains to be done. However, I would like to point out some aspects of our research where information was collected that we consider to be culturally specific, and other points where we are not sure if our data really reflects the reality. Exactly half of the disabilities of our basic sample of 200 people were caused by mine accidents. A little over a quarter of the disabilities (24.5 %) are the result of illness. Significant here, above all, is poliomyelitis. Of the illnesses, 39 percent were attributed to *feitico*, and thus to a deliberate attack, in the form of a curse by another person. In addition, in five cases such attacks were named as the direct cause of a disability. Notably, in none of the cases was a mine accident attributed to *feitico*. In relation to this question, the interview protocols do not fully correspond with information obtained from other sources which do connect mine accidents with *feitico*. This cause, however, is indicated far less frequently in this situation than for cases of illness. At the present, we have no secure basis for interpreting this phenomenon. It could possibly be due to the fact that the local culture has no explanations for the effects of modern warfare. Ideas about disability caused by a land mine accident might be similar to the word for mine in Chokwe, the regional language. The word does not exist in Chokwe though and the Portuguese word *mina* has been adopted into local speech from the official language.

SUBJECTIVE PERCEPTIONS OF DISABLED PEOPLE AND THE ROLE OF THE FAMILY

The family played an important role in gathering data. This was reflected in some of the questions but also in the fact that only a few interviews were carried out only in the presence of the person being interviewed. Members of the family were almost always there too. One hundred and fifty disabled informants answered the question of what was the most serious problem resulting from their disability. The fact that they could not adequately care for their family, especially their children, was indicated by 29 (19 %) of them. When we count those who answer that they are not able to work as before, for example as a person is supposed to work (*devidamente*), we now have 102 answers. This means that 68 percent see their biggest problem as not being able to fulfill their obligations to their family or their community. This corresponds to a high percentage of the responses of non-disabled family members. Included in the interview outline was a question about recurring dreams. This question was actually asked only fifty eight times. We received no convincing explanation from our interviewers for why they so often forgot to ask this question, which was not true for any other question. Thirty six times (62 %) the answer was given that the disabled person repeatedly had the same dream. These respondents dreamed that they were not disabled and that they could walk with both legs, in the case of amputations, or, in the case of blindness, that they were watching a movie.

THE DISABLED AND TRADITIONAL HEALERS

Disabled people were asked for their opinion of *Kimbandas*. In this area, the *Kimbanda* is synonymous with *Curandiero* – healer – and therefore not, as for example in some areas of Brazil, a mainly negative concept. Nevertheless, we received only eleven clearly positive answers (8 %). Ninety two percent of the responses indicate a lack of trust in, and rejection of, the traditional healers. Some respondents stated that they preferred the supposedly more scientific Western medicine, others answered that they never went to healers. This last response was given forty eight times (36 %). Thirty three respondents (24 %) answered that these healers were only able to cure traditional illnesses, such as sickness caused by *feitico*, and that for other diseases they were of no help, especially in the case of a disability caused by a mine. Ten respondents considered the traditional healers to be too expensive, eight (less than 6 %) simply stated that they do not like the *Kimbandas* and one respondent said that all they do is cause conflicts. These are four examples of statements containing culturally specific data. However, these statements indicate to us that the results of our data collection cannot simply be understood as culturally specific information in itself. We only recognize the problem when we take into consideration, in our evaluation of the results of the research, other kinds of experience gained through the work of the project. On the basis of this experience we know that people's attitude toward the *Kimbandas* differs from what our results seem to indicate. It seemed to us highly unlikely that 36 percent of the disabled people interviewed never went to a traditional healer. As a result of their direct experience, the workers in our project know that the local people, in situations of serious illness, see the *Kimbanda*, at least in addition to their treatment by a medical doctor. In this case the explanation for why the people who were interviewed answered in this way is very simple. Our interviewers, without exception, were from the same region and spoke the same language as the people that they interviewed. They came, however, as employees of a foreign NGO with the name Medico International. In Portuguese, this name conveys the impression that the organization has something to do with medical doctors (medico means doctor). The appearance of such an organization awakens the expectation of the availability of medical facilities. In order to profit as much as possible from these services, it is necessary from the start to establish a relationship with the organization that is as good as possible. Thus, their answers reflect whatever it is they imagine their listener wishes to hear.

HOW THE RESEARCH METHOD INFLUENCES THE RESULTS

This interpretation was frequently confirmed when we asked people about it. In retrospect, it seems so simple that we should have anticipated the problem. Thus, we made a mistake that could have been avoided. Possibly our information could have more accurately reflected reality if we had contracted with an Angolan institution, for example the School of Social Work in Luanda, to conduct the data collection. Also, the danger of this type of research has already been noted. Ingstad and Whyte mention numerous studies that were carried out during the International Year of the Disabled. "The very act of interviewing people about their infirmities raised hopes that something was going to be done for them. A consciousness about disability was created without any follow-through" (1995: 24).

OTHER SOURCES OF CULTURAL KNOWLEDGE

An understanding of the other examples only becomes possible when we include culturally specific information from additional sources as part of the interpretation. Thus, we can use information taken from the literature about the belief systems of Bantu cultures in general, and that of the East Angolan Chokwe culture in particular (Altuna 1985/1993; Redinha 1974). From the literature, we learn that, according to the view of reality held by the people that we are working with, a close connection exists between the visible and an invisible world and both are equally real. Every visible phenomenon corresponds to an invisible reality (Altuna 1985/1993: 64). What the Western person would consider a cause, is for him (the Bantu) the instrument of a hidden power. This does not mean that he denies causality. Just the opposite is true. The idea of causality is so natural to him that he applies it constantly, sometimes even obsessively (Altuna 1985/1993: 65). Even when he understands the effects of viruses and bacteria, or that of climate and anemia, he would never consider these as ultimate causes. In cases of misfortune, an invisible force is at work. The ill person goes to the hospital but, at the same time, he requires the help of the traditional healer who, by using his power, counteracts the malevolent magical cause of the illness. This behavior, which is logical according to cultural principles, paralyses these societies and leads to a certain fatalism, asserts the Angolan author Altuna in his book about Bantu cultures (p. 66). In the practical daily work of the project, this assumption led to one of our workers taking his seriously ill wife to a *Kimbanda*, after she had been unsuccessfully treated at the local hospital. He in no way justified this to us Europeans as being a complementary, alternative or even more natural form of treatment. Rather, he responded to the hopeful but worried questions about his wife's condition during this treatment, that this was a *different*, a *traditional*, method of healing, unknown to Europeans, and therefore he saw no possibility of letting me know anything about the success of the cure. He was supported in this by our entire group of co-workers who, at this moment, abandoned all the European-style logical thinking that they usually employed in their health education efforts in the village.

In the ethnological and anthropological literature, we find an abundance of indications of this kind which are also often contradictory. We accept them to the degree that they offer explanations for phenomena which we encounter through working with people as part of our project. This means that the study of the literature is necessary but not sufficient for a project carried out in an alien cultural context. Such information only has meaning for those people who, in the actual situation, have sufficient sensitivity and powers of observation to perceive the foreign. Along with this goes the ability to relativize one's own ideas about disability and the awareness that the concept of disability, in the Western sense, is not necessarily to be found in other cultures.

WHAT SIGNIFICANCE DOES CULTURAL KNOWLEDGE HAVE FOR THE ONGOING WORK OF OUR PROJECT?

When cultural knowledge is available – and I hope that I have made clear how difficult it is to obtain – what meaning does it have for the ongoing work of our projects? Through what we now know about the social and cultural conditions in Moxico Province in the eastern part of Angola, we see ourselves confirmed in our community oriented approach. Among other things, this involves more than just helping people who have lost a leg through a mine accident by providing them with an artificial limb. It also means, for example, making it possible for them to receive vocational training in small workshops together with non-disabled people and, thus, to be able to support themselves. We help them to rediscover agricultural methods and farming practices that were forgotten during the period of war and population displacement. We initiate and support cultural and sporting activities that allow the participation of disabled people. We create, in general, the conditions to contradict through experience the assumption that a person with a physical impairment has lost the ability to fulfill his or her social and familial obligations. In so doing, we experience over and over that we are not dealing with an intact culture, handed down from one generation to the next, but instead with something that is the result of a lengthy and thorough process of social and cultural destruction, and as a result, that poverty, competition between individuals and hopelessness have become fundamental sociocultural elements. On the other hand, we see the persistence with which the people interpret reality according to their centuries-old system of concepts and beliefs. For example, they consult the *Kimbanda* when they are sick or when their children undergo initiation. Even if they laugh when they tell us about doing so, we can see what power, despite all the attempts to destroy them, these traditional beliefs still hold. The constant presence of an invisible aspect of reality, the spirits of the ancestors, sometimes seems to us to be a barrier to the application of the efficiency criteria of our funding agency and to our own success-oriented project work. If we are sometimes hindered by these beliefs we can also see these barriers as reassuring evidence that the destructive force of our own culture, which is considered to be and presented as globally dominant, is amazingly limited.

DEALING HONESTLY WITH THE CONTRADICTIONS

Therefore, we have to be careful that the use of cultural knowledge in the work of our projects does not become a tricky process of so-called participant observation, in which our target groups can see their wishes and interpretations of reality expressed in a way that they can understand. The use of culturally specific information must become a basic part of our communication with every person that we work with in our projects. It is not our task, and is no way expected of us by the victims of war in eastern Angola, to act as if we are culturally neutral and only wish to serve their culture. We can, indeed, be very helpful in this by supporting a medical station in a village. If we, who rush to take aspirin in the event of the slightest headache, explain to the rural people in a village that they really should go to see the *Kimbanda*, we make ourselves ridiculous and are not taking those people seriously who do it anyway, if they consider it necessary. It comes down to offering to do what we can do. This involves showing them that what we can do is not more valuable than what their concepts represent. In the post-war situation in Angola, what we call psycho-social work has especially to do with making clear that, we too, have no solution for the manifold disability that the decade-long war has produced. Through this, we show that we all need to work together to overcome the problems. The experience of the people of Moxico will cause them not to believe us. We will, against our will and despite our own social and political origins, be associated with those who have ruled wherever they have appeared and have attempted to make dominant their own view of the world. Much patience is required if we want to get the message across that we want to do things differently. We will only succeed in this if we really want to be different, meaning that we abandon cultural dominance as an essential element of our own culture. It is debatable whether this is possible at all. It should be made clear, however, that the ongoing work of projects not only requires the consideration of cultural knowledge relevant to the alien culture. It also requires a culturally specific and critical consciousness of our culture, along with a willingness to take steps to modify our culture.

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SOCIO-CULTURAL REPRESENTATION OF DISABILITY IN TARGET GROUPS OF REHABILITATION WORK: EXAMPLES FROM *HANDICAP INTERNATIONAL* PROJECTS

Francois DeKeersmaeker

SHORT DESCRIPTION OF HANDICAP INTERNATIONAL

Handicap International (HI) is a Non Governmental Organisation, founded in 1982 in France, 1986 in Belgium, 1996 in Switzerland and 1998 in Germany. Its activities include projects for the rehabilitation of disabled persons (Physiotherapy and Orthopaedics with training of local staff and appropriate technology, support of local organisations of disabled persons, measures for social integration), and the campaign for the ban of landmines (lobby in our countries, mine awareness and demining in affected countries). It runs projects in over 30 countries affected by structural poverty, by war or by natural catastrophes.

INTRODUCTION

Rather than going very deeply into each example, we chose to look for some common points between the different projects of HI, so that from a multiplicity of situations we can go further into the question of defining better ways to consider effectively the specific cultural aspects in the work with disabled people. In order to get these examples, we compiled the internal literature of HI on the subject, but also sent a questionnaire to all the projects in the field, asking them about their experiences, methods, successes and errors. The results of this questionnaire were rich and interesting. However the main remark was: we need to work much more on this issue, and we need more solid inputs to do it correctly. All those responsible for and in projects showed great interest in sharing the results of such a Symposium.

IMPORTANCE OF CONSIDERING SOCIO-CULTURAL REPRESENTATIONS OF DISABILITY IN THE PRACTICE OF THE PROJECTS

- It will guide us in understanding what *Disability* and *Disabled* Person really means in the target group considered (knowing that there are no universal categories of disabilities, but clearly different situations of disability).
- It will help us avoid coming (as a foreign organisation) with a predefined and rigid solution or model, which may not be accepted by the supposed beneficiaries.
- It will force us to be flexible where we could be tempted to adopt standardised responses and methods (especially for an organisation working in many countries, the reaction is often: with so much experience, you must have developed some models).
- It will finally help us to be better integrated in a specific context and therefore to create better chances for the so called beneficiaries (all of them: disabled persons, families, self-help groups, local professionals …) to actively participate in their own rehabilitation, and even better, be very soon the real actors in the project.

As a first illustration of how deep the consideration can go we will give here an example from our team in Mozambique. One part of the programme is dealing with Cerebral Palsy children and their families in the suburbs of the capital Maputo. After several years of work with this group, the team slowly discovered specific linguistic aspects regarding this form of disability. In fact there are in one local dialect up to 27 different words to describe this phenomenon. Analysing the words showed that they express a very fine gradation in the explanation of the illness. The word used in each case will tell us if the child or its family are considered as a victim or as guilty of causing the disability. According to the origin of the disability (guilt or not), the social position and the acceptance of a treatment will be completely different. Through this example, it becomes very clear that the pathology evolves into a social or community problem, and the treatment will have to take into account this social component. We will have to work with the family on the explanation of the pathology, go through traditional social processes which will allow the disabled child to change from the guilty category to the victim category and hopefully find a socially/culturally acceptable way to get access to a (para)medical therapy. Another rather provocative example: starting a new programme in Albania this year (CBR, support to local networks for disabled people), we heard constantly "we are all disabled in this country", or "could HI do something for the politically disabled?" This shows how deeply the people there feel they need help at all levels, and that we probably should be careful and modest in our attempt to help one group of disadvantaged people rather than another.

DIFFICULTIES IN IDENTIFYING THE LOCAL BELIEFS AND ATTITUDES OR REPRESENTATIONS OF DISABILITY

Local culture or global context: most of the time, analysing the local situation shows that we are facing a complex patchwork of traditional explanations and socio-economic conditions determining in the last instance the situation of disability in each case. One example in the favelas (slums) of Sao Paolo (Brazil): the part of the city where a CBR project was started is typical for the difficulty of analysing the *local concepts*. Most of the population comes from other parts of the country, so there is no unity in the uses and traditions represented. Brazil is already itself a mixture of several cultures, and this mix is exacerbated in such a favela environment. Nobody trusts anybody, families are split, each one struggles for his daily subsistence: in this context people have no stable references anymore, and explanations as well as treatments for disabilities can be found in many different directions. Religious sects of all types, candomblé, voodoo, new reformist church, all of them are possible recourses for extremely isolated people.

Local disparities and contradictions in the same society: the way the different groups concerned see the disability is not unified. Disabled persons, war veterans, health professionals, local authorities and community will not have the same approach to the interests of disabled people. On the other hand, evolution in the way of dealing with disability may also vary within the same country, and those differences are sometimes ignored by our local partners in project countries. To give an example: during an evaluation visit to Guinea after a request from the local Ministry for Social Affairs, we could feel the big gap between what is being organised in the capital of the country and what is the reality in the more remote provinces. One the one hand, the country is striving for modernity and wants to provide disabled people with modern facilities in a modern system of service delivery. On the other hand, most of the people still live with strong local traditions and representations which are not compatible with the modern systems. In this case, the lack of consideration of local concepts is reinforced by local actors (the politically responsible, educated health personnel, NGO leaders etc.). Finding a middle way becomes a real challenge.

The interaction between actor (especially in the case of a foreign agency) and the beneficiary group inevitably affects the perception of disability in the beneficiary group itself. There is an automatic dominance of our models because of the power that we represent whether we want it or not (money, material, supposed welfare in our countries), be it in a positive or in a negative way. To give an example: a new programme of home visits in some suburbs of Maputo in Mozambique has changed the attitude of mothers with their disabled children. The presence of a disabled child was until then the cause of the isolation of the mother. And suddenly, people came to visit her because of the same disabled child.

The pressure to produce results coming from funders, local authorities, the pride of the project's own leaders, put the project under pressure to produce results, as quickly as possible and as visibly as possible. This leads most of the time to an exclusively quantitative analysis of the situation. To give an example in Rwanda (1995). HI wanted to carry out an analysis of the situation of disabled people in the aftermath of the genocide: who is considered as a disabled person in this particular context, how do the rest of the communities deal with them etc. Because of the funding conditions and the wishes of the governmental partners, the study ended up in a rather quantitative survey of predefined classical categories of disabilities, without real analysis of the particular situation of disabled people in Rwanda after the massacres.

WAYS AND METHODS OF IDENTIFYING LOCAL REPRESENTATIONS OF DISABILITY

HI has no recipe to propose. In 15 years and 30 countries we have had lots of trial and error, we suffered sometimes from lots of frustration, we often had to react rather than to act. Those trials, errors and successes built up our experience and our know-how. One thing is important to accept: there is no ideal method and no ideal moment in the project's course to realise the process of identification of the local representations. The process must be on-going and accompany each moment of the project. The actors must be open to further research, and leave space for questioning. There are however a few things that can be pointed out as the general response of HI in its projects:

- Preparing a new programme presupposes an in-depth situation analysis of the region for a possible intervention. After contacts with the local partners, an *exploratory mission* will assess the situation as a whole (political context, economic and social situation, regional differences, governmental and non governmental structures, situation of the disabled person etc.). A Guideline (*Guide for Situation Analysis and Needs Assessment*) is used for such missions.
- European volunteers receive a one month specific training before starting a mission overseas (intercultural concepts, role-plays, visit to another project etc.).
- The purpose of a project is not to act on a specific and predefined category of disability (polio, amputation, club foot etc.) but to act on the different levels that are responsible for a situation of disability (physical deficiency added to a lack of mother and child care systems, poverty in the family, cultural discrimination, absence of political will etc.). Access to school for a child with disability can help him in some cases more than merely physiotherapy treatment; preventing mine accidents by demining and mine awareness projects are just as important as fitting prostheses for the mine victims. This comprehensive approach to disability leads HI to plan projects with comprehensive development goals.
- Using the concept of *Appropriate Technology*. This implies that you should know first what is appropriate (locally available competence and material).

We can also report on some specific responses, where an in depth effort has been made to get the best possible perception of disability. Specific action has been taken most often after a certain period of presence in a project after observing unexplained resistance to the services proposed, or before starting a new component of an existing project. We choose here three examples which reflect three relatively different methods.

- Chad: After 1 year of work with Handicap International, a French physiotherapist and anthropologist decided to carry out a real ethnological study in the south of Chad. For three months, together with two local researchers, he visited the local traditional healers to discover their concepts of disability and their healing practice. The results show first of all that representations of disability are as difficult to isolate as in our culture, because they depend on the whole social organisation and on the exercise of the power. It demonstrates that modernity and tradition continue to live side by side. Traditions are often hidden, but they continue to explain and organise hierarchy and power distribution. Therefore, explanations of illness and disability will induce specific social behaviour that has to be respected before or at least parallel to a *modern* intervention.

- Central African Republic (CAR): a few years after the start of a rehabilitation programme throughout the country, the actors (local PT's) felt resistance from the beneficiaries or noticed unexplained interruption of the treatment. They tried to find an explanation for it and organised a seminar on the question in different regions of the country. They gathered important information about representations of disability and could better understand why people were sometimes reluctant to treat their disabled family members. The two main aspects were the magic origin of the disability (penalty imposed by a sorcerer for bad behaviour or witchcraft from someone as revenge or due to jealousy) and the poor economic contribution to be expected from a disabled family member. In the first case, it means that one should not interfere in magic/witchcraft processes, since the counteraction could be even worse. In the second case, it means that no investment in money and time should be made for a person who doesn't guarantee any income for the family in the future. The programme had to take these elements into account. They decided to focus much more on sensibilisation on the one hand (giving an explanation based on physical phenomena can help demystify and alleviate feelings of guilt; showing the possible autonomy of the disabled person after treatment can give hope that the disabled child will also help in family life) and on integration of traditional curative solutions when possible on the other hand (hot tree leaves on the legs of the child in traditional therapy; hot towels to diminish muscular pain in occidental therapy). From now on in Central Africa, HI is promoting such subjects for students of PT at the end of their studies.
- Mozambique: for her complementary diploma a French PT, back in that country after 8 years, carried out investigations for her complementary diploma and analysed the local representations of disability with open interviews. Here again, the notions of guilt and passive victim were very important to determine the attitude of the family/community towards disability.

What Can We Learn from a Better Knowledge of Local Beliefs and Concepts?

A social approach rather than an individual one is the only way to prevent disability and alleviate consequences of an existing disability. It is imperative to avoid a product approach, often driven by emergency situations (our knowhow is our label, as a product that we would only have to deliver). Try to take care rather than provide care. It helps us to better identify of the *target group*: it is not only the patient her or himself, but maybe first the mother, the father, the family etc. Reorientation of the programme's main objectives is sometimes necessary: first sensibilisation, then treatment. It stimulates a greater participation of the beneficiaries (patients, professionals, communities etc.), and most of all, it gives better chances for a real appropriation of the project by them.

Conclusion

The method is not the most important. An open mind and permanent questioning are the keys to a better knowledge and understanding of local concepts and beliefs about disability. Adopting an attitude which considers disability as a comprehensive situation (in a specific context, in a specific society and experienced by a specific individual) gives greater chances to the foreign actors to propose the appropriate solutions and for the beneficiaries to understand how they can help themselves rather than accept disability as fate.

INCORPORATION OF KNOWLEDGE OF SOCIAL AND CULTURAL FACTORS IN THE PRACTICE OF REHABILITATION PROJECTS

Dee Burck

INTRODUCTION

Never have I been more aware of the social and cultural factors in the practice of rehabilitation projects than at the time when I had just returned from Zimbabwe. I worked there for four years, in a project on community based rehabilitation and conducted research for my PhD thesis entitled *Kuoma Rupandi, the parts are dry, ideas and practices concerning rehabilitation in a Shona ward.* After my return to the Netherlands, I was in charge of a nursing home, which, in the Dutch setting, also offers rehabilitation services. In the CBR project there were clients who had to walk on hands and feet for miles in order to be able to attend the training and income-generating projects organised. My first meeting in the Netherlands, when I was in charge of the nursing home, was with a group of unhappy residents who wanted me to replace the elevators because the buttons in the elevator could not be reached sitting in an electric wheelchair.

In this article I will assume that the readers all have had similar experiences, whereby differences in social and cultural perception influence the practice of rehabilitation projects. Illustrative as these different experiences and examples may be, I do not want to dwell on them too much but, instead, want to pose some questions that will hopefully bring our discussion beyond the level of individual examples and experiences: What are the social and cultural factors that affect the practice of rehabilitation projects and how can we differentiate between them? On the basis of a number of concrete examples, we will try to analyse how a different interpretation of important social and cultural factors may contribute to communication problems between rehabilitation worker and client, thus hampering the rehabilitation process. Furthermore, I would like us to agree that there is a need to include knowledge about social and cultural factors in the practice of rehabilitation projects. Thirdly we will try to analyse why it is sometimes so difficult to include knowledge about social and cultural factors in rehabilitation projects. Finally I would like to discuss what could be done to overcome these obstacles. With respect to this last point, I would like to play the devil's advocate a little bit, urging the reader to indicate clear priorities and preferences.

SOCIAL AND CULTURAL FACTORS AND HOW TO DEFINE THEM WITHIN THE CONTEXT OF REHABILITATION PROJECTS

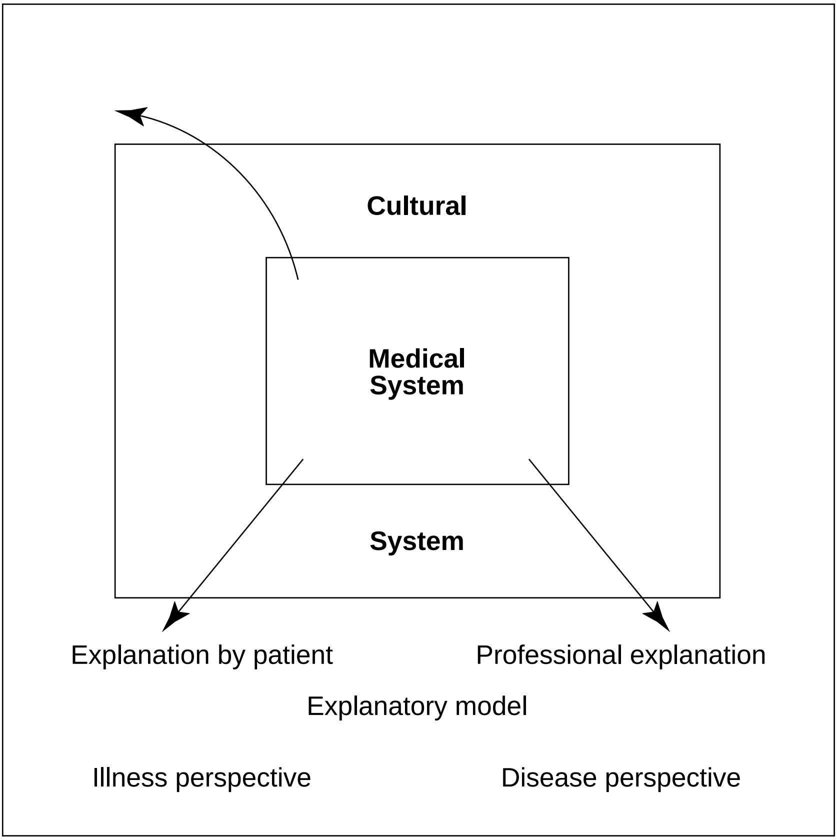
Social factors determine group membership: status, role, position. Group membership determines to a large extent one's perception of the world. Social factors or rather differences in social group membership play a role in almost all client – health worker relationships. It is related to what Kleinman (1980) and others (Press 1980; Eisenberg 1977) have differentiated as the illness and disease perspective, respectively. The explanatory models that health professionals use, whether these are Western style physiotherapists or traditional healers, are different from the perspective of the client. Only when the health care provider is disabled himself or herself and can incorporate the illness perspective into his more professional view, or when the disabled client pursues a professional career in rehabilitation medicine, can the illness and disease perspective be brought together. It is more common however for the two perspectives to differ. In a normal *therapeutic* relationship the client expects from the health care worker the added value of professionalism, summarised by Murray and Chavunduka (1986) as including the following key factors:

- Autonomy towards clients (financially)
- Monopoly in the professional field
- Code of ethics
- Body of knowledge

Cultural factors are related to ideas (knowledge, beliefs, values, norms) with which we structure our experience and order our behaviour (Berger and Luckman, 1976). At the same time, individuals influence and shape culture and the values and norms incorporated therein every time they show their specific choices and interpretations in the form of concrete behaviour; because as individuals we may be guided by norms and rules, but we do not stick to them and that is how norms and rules may gradually fade out and be influenced or replaced by new ones. This is also how traditional ideas about illness and disability will change, when more disabled persons in developing countries are brought into contact with *modern* medical rehabilitation services.

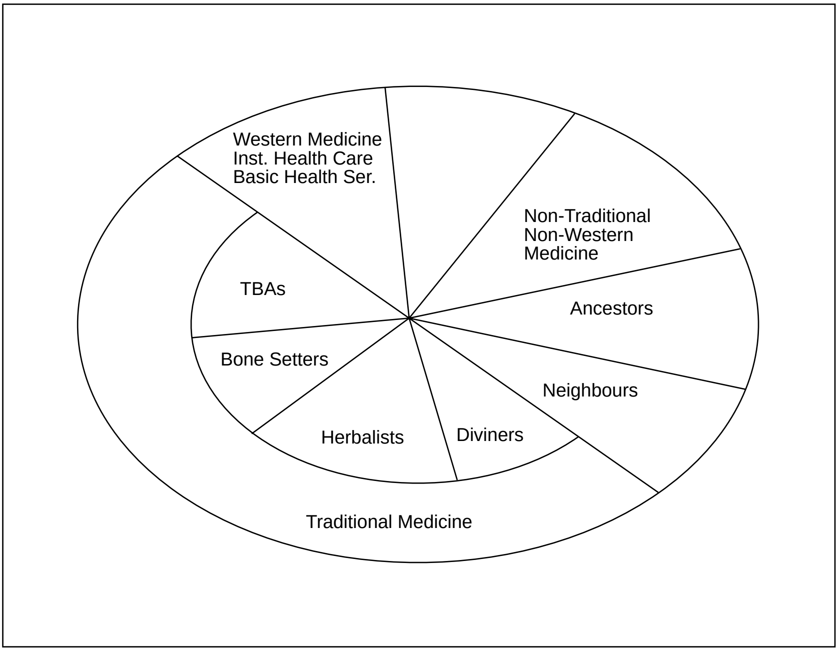
Cultural differences play a role particularly if health worker and client belong to different cultures and to a lesser extent when they belong to different sub-cultures. We will assume that the sub-cultural differences merge with social differences. If health worker and client belong to different cultures their medical explanatory model will have its base in a different cultural mode.

Table 1: Sickness/Folk Perspective (Kleinman)



Each culture has its own medical system. A medical system may be defined as the organised system of ideas and practices concerning illness, a system which is grounded in and derives its structure from a given cultural context (Kleinman 1973: 57). Within one cultural and medical system, different explanatory models may occur. Here we distinguish between the explanatory model from the patient and that of the professional.[1] When a disabled person visits the hospital in the morning and the traditional healer in the afternoon, this does not imply a shift from one medical system to the other medical system. In actual fact these shifts from one type of health care provider to the other take place within one medical system. Within the medical system the different categories of health care may be seen as different pieces of pie from which the client may choose.

Table 2: Different Categories of Health Care



Each medical system has its own *pie*. In Western culture the modern or Western medicine constitutes a larger part of the pie than in developing countries, but in the West our medical system also has different *tastes*, such as homeopathic medicine, acupuncture, ayurvedic medicine, faith healing etc.

Cultural differences play a role particularly when outsiders come to a country to perform rehabilitation services or to develop rehabilitation activities or when people belong to different sub-cultures. The most extreme consequence of this argument is that a person who is a cultural outsider will never be able to perceive and experience the medical system as an insider does. To put it differently, if we had enough disabled rehabilitation workers in each of the developing countries, interpreting disabilities within the context of their own cultural and medical system, the lack of knowledge about social and cultural problems would automatically be reduced.

HOW SOCIAL AND CULTURAL FACTORS INFLUENCE THE PRACTICE OF REHABILITATION PROGRAMMES

When we talk of social and cultural factors, what exactly do we mean? We mean factors that are relevant in one or the other explanatory model. Some examples from the material I collected for my PhD study:

Social and Cultural Factors Influence the Definition of Disability and Determine Who Are Considered Disabled and Who Not

After some time, in my research, it became clear that my taxonomy of disabilities did not make much sense to my informants. When asked to list the disabilities they recognised, in order of importance, conditions were included that would not generally be considered a disability in my system, while other conditions were left out when they should have been included, from my perspective. To give a few examples of conditions that were included: children who got their upper teeth first; throughout my fieldwork area this was considered a very serious disability that would affect a person throughout life; mothers who had borne a handicapped child were considered disabled etc. Function loss, which is an important determinant in our Western taxonomy, only played a minimal role. In actual fact it was not function loss, but the *dryness* of the affected part which determined the seriousness of the disability. These findings are supported in literature about general medical classifications, for instance Pool, 1989.

Social and Cultural Factors Determine the Explanatory Model that Is Used

The longer an illness lasts, and in this respect disability was considered an illness that lasted very long, the stronger the belief that the source of the problem lies in the social environment and not in the human body. Whereas in our endogenous health system we look for the source of evil within ourselves, other medical systems put the source of evil outside the human body. In such a case, the physical condition (e.g. disability) is seen as a symptom of an underlying social problem. The case of Maureen Mapfumo (the name is fictive) illustrates this: Maureen Mapfumo was about 20 years old when we met and she suffered from severe epileptic fits that had caused hemiplegia and blindness in one eye. When Maureen fell ill, around the time when she went to school, the family had consulted several traditional healers, without any result. It was implied that the family did not agree with the diagnosis of the traditional healer. We tried to convince the mother to take her daughter to the rural clinic, so that she could be provided with medicine to control the fits of her daughter. The mother seemed motivated to do so. We actually went along for the first visit and urged the mother to come again after four weeks to get new medication and to adjust the dosage. When we returned it appeared that neither mother nor daughter had visited the clinic. With renewed efforts we talked to the mother and to Maureen once more, but in vain. When we were returning from our third visit, which confirmed our earlier findings, a neighbour walked us back to our car and told us the following story: an uncle of Maureen killed another man in the village, and a dispute arose between the two families; Maureen's family claimed that their man had acted in self defence, the family of the victim claimed it was a brutal murder and they claimed revenge or compensation. The case could not be settled easily and this affected the whole community. When Maureen fell ill, the ancestors on both sides diagnosed this as a sufficient compensation. The family of Maureen will not openly admit it, but they have accepted this verdict. They are afraid that, if Maureen gets cured, the whole thing will start all over again. The case of Maureen Mapfumo concurs with findings by Ingstad (1997), who concluded that for parents of disabled children in Botswana, the disability itself was not shameful but the underlying cause of the disability often was a cause for shame.

Social and Cultural Factors Influence the Definition of Rehabilitation and Its Objectives

In my research, the most important criterion for integration was whether you were married and had children. Our project could provide a disabled person with a sewing machine to make him economically independent, but not however with a lobola (brideprice) to enable him to get him married. There is an example of a project in Africa some years ago, which was quite successful in assisting blind men to become economically independent. The men were involved in various handicraft activities and when I visited their centre I noticed that the handicrafts they produced did not sell much. Nevertheless virtually all the men left the vocational rehabilitation centre after their training period, settled independently in the village and managed to sustain themselves thereafter. Finally it was revealed to me that, while at the training centre, virtually all the men were married off to women who had been divorced or widowed and who had been working in the centre as cleaners. This aspect of the project had never been revealed to the donors however, as they might have opposed this marriage broker role of a rehabilitation project.

WHY IS IT SO DIFFICULT TO INTEGRATE SOCIAL AND CULTURAL KNOWLEDGE THAT EXISTS INTO THE PRACTICE OF REHABILITATION PROJECTS AND WHAT COULD BE DONE TO OVERCOME THESE PROBLEMS?

Incorporation of social and cultural knowledge into rehabilitation practice is a means to an end. In rehabilitation, gaining social and cultural insights will never be ends in their own right; therefore in projects they are bound to get only secondary attention just like gender, ecology, integration etc. This effect is further strengthened by the problems generally involved in multi-disciplinarity and inter-sectorality: the different categories of scientists and health workers involved in rehabilitation do not speak each other's languages, e.g. their questions are formulated in a different language from the answers. Social scientists cannot come with the ten golden answers to the ten most burning questions of rehabilitation workers and vice versa: the goodwill is there but it is more complicated to accomplish than we initially may have thought. Understanding a different social or cultural perspective is a process whose results cannot easily be summarised and conveyed to third parties that have not participated in this process. Some things cannot be learned; they have to be experienced. A lot of the knowledge and experience exists in Africa and Asia, but it has not been written down, it is not published and shared. E-mail and internet offer us possibilities to share and exchange experiences in a less formal way (than a scientific publication that is) and with a much broader audience. In my perception the real problem is not at the level of the individual health worker. Reality will force him/her to struggle along and find practical solutions. The problem is rather at the level of managers who, and I am now providing literal quotes from my own career, "do not need a god-damned anthropologist to run their programme" and who write to you, "if you want this project to be still there next year, you better forget about these cultural hang-ups and come up with some success stories".

What steps should be taken to gain more knowledge and to get this knowledge included both in the design and implementation of rehabilitation projects? This question can be answered in many different ways and in fact during the conference in Bonn (cf. Introduction) many different approaches were discussed. There are more ideological approaches, aiming at greater influence of disabled persons themselves. There are more practical approaches that take into consideration the present organisational and financial constraints. I would like to argue for a combination of approaches. Let us not argue too much among ourselves, but let us try all the approaches that work more or less in the same direction: optimal integration. Conflicts of interests between health care professionals and their clients are bound to occur, but can be solved on the spot or, if the need arises, can be brought forward in forums like the Bonn conference.

From a more practical perspective, I would recommend the following action:

- Train more rehabilitation workers in developing countries themselves.
- Train rehabilitation workers not only in technical skills but *where there is no anthropologist* also as social scientists, as listeners, as observers.
- Strengthen self-organisations of disabled persons so that their needs and problems can be heard as directly from the horse's mouth as possible.
- Social scientists and rehabilitation professionals should carry out research programmes together.

NOTES

1 Kleinman (1980) also distinguishes the folk perspective, which may be seen as some sort of generalised lay-perspective, leaving out the personal influences of the patient perspective.

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THE IMPORTANCE OF CULTURAL CONTEXT IN TRAINING FOR CBR AND OTHER COMMUNITY DISABILITY SERVICES

Sheila Wirz

INTRODUCTION

The arguments of this chapter have relevance not only to CBR, a form of service delivery associated with the majority world, but have equal relevance to community disability services in the West. This is the reason why the chapter title refers to CBR and *other community disability services*. The chapter addresses the issue of how the cultural pluralism of trainers and trainees affects the training process. There are many definitions of CBR and the CBR movement gathers great strength from this diversity of interpretation. This chapter takes the Joint Declaration (1994) as a working definition of CBR. The advantage of this definition is that it is not prescriptive and leaves flexibility of interpretation for programme planners and trainers and educators.

> Community Based Rehabilitation is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services. (ILO, UNICEF, WHO, Joint Position Paper, Geneva 1994)

There is a continuum of interpretations of the Declaration reflected in very different ways, from those who interpret rehabilitation as a human rights issues at one end of the continuum to those with a technical rehabilitative focus at the other. By way of introduction I will review the differences of expectation which I believe people bring to the training process. I will then draw upon experience from CICH and from the literature as to the ways in which different constructs can affect the way in which people perceive, plan and train for CBR. An important determiner of these different expectations is peoples' experiences of disability, of the community and their personal technical skills. This discussion is divided with reference to:

- expectations of training
- expectations of services
- expectations of the rehabilitation process

EXPECTATIONS OF TRAINING

Training for CBR encompasses a wide range of training activities. The training of first level CBR workers (sometimes referred to as *grass roots workers*) must be undertaken at local level, to accommodate to local variation, since the experts who can conduct such training are local. They are unlikely to be sitting at a seminar table in Bonn. Comments in this chapter therefore relate to training of trainers or of professionals who might become involved in CBR. Training for such people is frequently international, with heterogeneous groups from a variety of countries, with very different experiences of disability and of how and why training is provided. If training is to be successful it is vital to consider participants' expectations of the objectives, the process and the outcomes of training, as well as participants' expectations of the content of training.

The expectations of the objectives of training for the trainee may include becoming able to do the job better, having enhanced career opportunities and/or higher salary, the chance to be away from home and the day to day activities of the job, the opportunity to stand back and consider strategic moves of a personal or service nature or improving the lives of people with disabilities. Difficulties arise when the huge variation of expectations for undertaking a course are not examined early. In some cultures, the opportunity to take a course of study away from home is seen as an opportunity for personal enhancement and the nature of the training, whether it is a CBR trainers' course, a human resources training or a social policy course is somewhat irrelevant. For such a candidate, completing the course is the objective rather than the learning opportunities offered by the course. Such a course participant may be unable to be frank about his/her motivation for attending the course and almost certainly does not share the expectations of other course participants, who have either saved hard personally or striven to seek funding in order to achieve a place on the training course, nor with the course leader who, at some level, hopes that all participants are there for altruistic reasons.

Similarly there is equally wide variation in *the expectation of the process of the training.* Depending upon the cultural experiences of group members there will be a wide variation between those who expect the training process to be active or passive, curriculum led or learning centred or to follow an expert model of learning as opposed to participatory learning. In many cultures in developing countries, learning is seen as a passive activity, decisions as to what is to be taught are made in advance and participants follow the course, rehearsing and regurgitating closed answers to closed questions in order to demonstrate that they are learning! Such a *cook book* approach to learning is very seldom successful in any domain, but is doomed as an approach for CBR, which relies on developing the creative skills of people. Similarly, in cultures which are resource poor and large class size is the norm, especially at school, students are expected to follow a prescribed curriculum where the course leader or teacher is seen as the *expert* and the participants as people who *absorb* the expertise.

At CICH course participants following Masters degree and Diploma courses are from both developing countries and from Western countries with work experience (often with NGOs) in developing countries. The first group are often used to passive learning following a curriculum led model with expert input. There follow three examples of recent quotes from students who found the interactive style of teaching at CICH difficult when they first arrived in London,

- *"I find it difficult to challenge the Tutor"* (28 year old from India);
- *"I have never been expected to argue with the teacher"* (32 year old from India);
- *"In my culture I cannot disagree with the teacher"* (39 year old from Southern Africa).

Such comments are very typical in early tutorials with new students from the South. In contrast the participants from the West are often paying for the course themselves and challenge the value they are getting for their money by demanding variation and tailor made adaptations to meet their individual needs. The cultural diversion which leads to this variation of expectations must be addressed if the needs of those participants who are conditioned to accept a passive role are not to be eclipsed by those of their more forceful peers who have such different expectations.

A third area where cultural expectation of training can differ greatly is the expectations of outcomes of the programme. If early experiences of schooling and learning have been dominated by passive learning and didactic (expert centred) teaching, then the participants' cultural expectation is of *knowledge*. The tutor will design a course which explains the *facts* to the participants. Students commit these facts to memory and relate them as proof of learning. Such a cultural expectation of *knowledge* as the outcome of learning is very different from a Western expectation that all experienced participants will bring to a course wide experience of life, of local culture and of disability and that the outcome of the course will be a developing confidence in the validity of these experiences and in the ability to problem solve issues related to CBR.

Similarly, there will be variation among students' constructs of what the course content of a training course should be. Some participants will expect a course to produce facts and others to develop their ability to know where to find answers. Some will expect a course to develop skills, others to improve their confidence as practitioners. The need to explore expectations by course participants and an understanding by the group of how their different cultural experiences have influenced these expectations is essential if any group with diverse cultures is to work well together and all are to achieve their learning goals. Time has to be set aside to ensure that this exploration happens or the dominant group members or an insensitive tutor will impose their constructs upon the group, in sharp contrast to the ethos of CBR. It is also worth asking the question where international courses should be held. There is value in enabling people from a range of countries to come together in an environment where they can share and learn from each other. At CICH we believe that for skills based diploma courses this should be in a country where there is academic expertise and good local experience of CBR. In the last few years we have worked with colleagues in Uganda and in India to ensure the sustained development of international courses there. We hope there will be others.

EXPECTATIONS OF SERVICE

CBR has a wide diversity of interpretation, from the initial model of CBR as conceived by WHO in the 1980s and culminating with the publication of the WHO Manual (Helander et al. 1986). There are other interpretations of CBR, e.g.

- emphasis upon early childhood intervention (Thorburn 1991),
- the use of volunteers in a small country with a commonly held expectation of voluntary activity (O'Toole 1991 in Guyana),
- the emphasis upon local community committees in the Middle East,
- devolving CBR activities from institutions (Carpentier 1994).

Culturally appropriate models of CBR have arisen to meet local need. It is interesting that the most widely written about CBR activity developed by disabled people themselves, at Project Projemo (Werner 1985), has never been replicated. On the one hand it seems sad that such an excellent sounding model has not spawned others, on the other one has to accept that Project Projemo, however successful in rural Mexico, was not culturally appropriate to other settings. The lesson, fifteen years after the first moves toward CBR, as a way of ensuring culturally appropriate, affordable and accessible services for disabled people through CBR, is acceptance of cultural diversity as to how CBR is interpreted in different settings (Mallory et al. 1993; Jaffer/Jaffer 1990). In the U.K., an energetic literature written by disabled people has emerged over the past 15 years. Oliver (1992), Morris (1991), Davis (1996) and many others have changed attitudes hugely through their work so that there is now an expectation that disabled people (DP) will be involved in planning, running and managing services for and with disabled people. The disability movement in the U.K. has moved thinking away from a curative medical model of disability towards a social model. Disabled colleagues in the U.K. would stress that we have not moved far enough and that the involvement of DP in planning and managing services is still too limited (Shakespeare 1997). This may be the case but disabled people in the U.K. have changed constructs. These changes of construct may be more limited than disabled people would like, but the arguments, vocally expressed by many disabled people, have persuaded many (perhaps even the majority) in the field that the *pity and charity* construct of disability is inappropriate.

There are other important changes which have influenced constructs in the U.K. and other Western countries. For example, the *Community Care* initiatives and *Direct Payments* and *Disability Discrimination* legislation as well as the movement towards Inclusive Education for children with disabilities over the last eight years in the U.K. may be criticised for being too limited, but they have raised awareness throughout society about disabled people. People with disabilities, including those previously *invisible people* with learning difficulties and multiple disabilities are seen in most settings. The fact that one sees people with multiple disabilities in most supermarkets in the U.K. has probably done more to change public attitudes than any other single fact. In the U.S.A. too the Independent Living movement has helped to change attitudes. I believe that this two pronged influence, on the one hand by articulate disabled people writing about disability issues, and on the other the change in legislation, means that peoples' constructs about disability in the U.K. have changed.

Croft and Beresford (1993) remind us though that the mere involvement of disabled people is not always enough: "not all involvement is necessarily empowering" (1993: 19). This is an important caveat to any complacency for activists in the North. Disabled people have had less success in influencing legislation and attitudes in many countries of the South, with notable exceptions, especially in post conflict settings where disabled veterans (former guerrillas/freedom fighters) have formed active disability lobby groups. This means that people coming to an international training with Western experience often have very different constructs, at the start of a course, from those whose experiences of disability are still influenced by professional dominance in planning.

In addition to different constructs of how different societies consider people with disabilities there is also cultural variation as to who is considered disabled. Vreede (1998) refers to this as ADL, IDL, ODL (1998), Wirz and Lichtig (1998) note the contrast between two pairs of siblings. The one pair with a 10 year old boy with mild/moderate learning difficulties in a rural African society with 30 percent school enrolment and his sister of 12 years unable to raise her arms above elbow height. In this pair the boy was able to help with goat herding and other tasks of his peers, whereas the girl who was unable to lift, to carry on her head or to pound grain, was considered disabled. In the case of an identical pair of siblings in London, with 100 percent school enrolment and supermarket shopping for food, the boy unable to keep up with the learning activities of his peers, would be considered disabled and the sister (with the slight modifications which she and her mother would have to make to her choice of clothes to avoid over the head dressing) would be able to undertake all the activities of her peers and would therefore not be regarded as disabled. The constructs of *disability*, and of *who is disabled* differ, and are created by our societal experiences of disability and hugely influence how services are construed by a society or community. It is vital that this variation is explored at the beginning of an international course if the group experience is to be equally valid for all course participants.

EXPECTATION OF SERVICE PLANNING

Course participants arriving from command regimes have few expectations or skills as regards the collaborative planning of disability services. In such regimes, planning of government service is national with little, if any, local variation and little *consumer input* to the planning process. Disabled people and their families are considered as recipients of service and CBR workers and others working in the rehabilitation process are seen as implementors of a national programme. In national programmes there is often a search for geographical parity rather than good coverage. In direct contrast many NGO services demand a commitment from the community before they will start a service and that service is jointly planned by NGO and Community, e.g. Seva in Action (an NGO in Karnataka State, India) (Rayjendra 1998: 54). Among those in the NGO sector there is often pressure to bring the needs perceived by a local NGO to the planning process when they may be in opposition to those of an international (donor) NGO (Jennings 1997). This introduction has explored how cultural variation affects what participants bring to a training programme in terms of their expectations of the objectives for training, the process of training and the outcomes of the training. Such pluralism is the challenge for international courses and the management of this pluralism to ensure that all participants gain from the experience is as least as challenging as the organisation of course curricula and evaluation. The remainder of the paper will concentrate upon cultural variation of the terms *the community*, the *rehabilitation process* and the *rehabilitation professionals* and the measurement of the success of a programme.

COMMUNITY: THE C IN CBR

Community Based Rehabilitation is predicated on the expectation of community involvement or, at best, community ownership of the programme (O'Toole 1991; Werner 1997). Before this very basic premise is assumed it is necessary to explore the nature of *community*. A question which has to be answered is how does one involve community when the expression of views is politically difficult/impossible? How does one stress the C of CBR in such settings? There is a commonly held maxim within the CBR literature that so called *bottom up* planning is inherently better than *top down* planning. This may be true in a setting where there is genuine freedom of expression and communities are not fearful of expressing what they feel (as opposed to that which they feel they should express!) The government of India proposed a *top down* plan for CBR through their DRCs (District Rehab Centres) with a range of services and staff flowing from that. In a subsequent evaluation after 10 years they were open enough to recognise that there was a gap between the DRC service and disabled people's awareness of how to access these services and to revise national planning with this knowledge (Rajendra 1998).

Coleridge, writing from Afghanistan, points out that while international NGOs may follow the view that their work should respect local values, at times

> local cultural values in Afghanistan conflict with their own values and indeed their own ethics ... discussion about cultural values is often regarded as too sensitive to even embark on ... resulting in activity initiated by foreigners which Afghans receive but which they themselves do not initiate, let alone control. (Coleridge 1998: 1)

It is very important to separate cultural variation from politics. Rehman (1997) shows that it is quite wrong for Western workers to assume that veiled women in the North West Frontier province of Pakistan are either unwilling or unable to take part in group planning activities for CBR because they are *not allowed* to do so by their menfolk. She shows that if care was taken in the planning of meetings women would attend, and be contributory and outspoken about their needs and those of their disabled children (Rehman 1997).

In much writing about CBR there is an assumption of common community values which must be met by the CBR programme. In reality values may differ within a geographical community by caste, by educational/economic status, by minority group (including the diversity which arises in some countries because of the mass migration population movements), and this diversity of values must be described in the planning process. This requires great skill by either a foreign NGO worker or by an indigenous planner who will both bring their own cultural norms to the process. CBR is impoverished by a lack of sociological or anthropological literature. Ingstad and Whyte in their 1995 volume have brought to a wider readership issues of cultural diversity regarding disability (Ingstad/Whyte 1995). Cultural variation has seldom been recorded by people working for and with disabled people in countries of the South and the passing on of knowledge (which undoubtedly exists) depends upon the unreliable transfer of knowledge through conversation. Orally transmitted knowledge of cultural values can be inaccurate either in the telling or in the understanding but is also in danger of being out of date. The idea of the disabled child being sent *back to the grandmother in the village* may have had some reality 15/20 years ago but observations in a CICH project in Dhavari slums in Mumbai (with the Spastics Society of India) suggest that the modern 40 year old grandmother (herself an urban migrant) is no longer the easy recipient of the role which her mother may have adopted.

Early recorded CBR programmes such as those of WHO (1983) and Werner (1985) were, in their different ways, culturally aware, stressing the need to involve the local community, to use local skills and resources and to address the local needs of disabled people and their families. They both aimed to foster independence for the disabled person. Independence is a Western value. Most of the literature by disabled activists in the West stresses the need for independence for disabled people (Swain et al. 1993; Morris 1991; Werner 1996), yet interdependence is the goal of many people of the South (Lang 1998a; Al Shehery 1995). Are CBR trainers and planners too greatly influenced by the articulate writing of Western disabled activists, believing that these are the shared values of disabled people from other cultures, without considering whether independence or interdependence is the goal relevant to that community? CBR trainers and planners of other disability services need to be sure of the relative value placed upon independence or upon interdependence by the society if the planning is to have cultural reality.

A further cultural difference which has an impact upon planning is whether conformity or diversity are valued within a society. If conformity is greatly valued there may be greater difficulties for disabled people and their families than in communities where diversity is valued. An important question for the sensitive planner to ask is, who is the guardian of this conformity? Is it the Islamic menfolk (Rehman 1996), Indian mothers in law or the state? Tembe (personal communication in London 1995) reports that physically disabled people in Mozambique are not eligible for a driving licence even if their impairment is relatively mild. Dlamini (personal communication in London 1997), in Swaziland, reports that unmarried people remain *children* in the eyes of both the state and of many people in the community and as many disabled women do not marry they are viewed as children throughout their lives.

It is important to differentiate between the state and the community. The state impacts upon the lives of disabled people in many ways and at times this impact may contradict the views of communities within that state. For example there are a number of international documents which can affect the lives of disabled people, e.g. the Standard Rules (1994), Declaration of Human Rights and Declaration of Children's Rights, all of which have clauses which protect the rights of disabled people. Many countries have signed such documents but without an independent (free) judiciary to which disabled people can take their concerns about violations of these stated rights such documents have limited value in improving the position of disabled people. Alternatively, individual state practice may conflict with community views regarding disability. Lang (1998b) cites the example of the Rehabilitation Council of India (RCI), which was established as a statutory body to register all training courses for people working with disabled people. Lang suggests that "this measure is in direct variance with the underlying philosophy of CBR, of enhancing and utilising indigenous resources in the community" (Lang 1998b: 23).

It is important to beware of imposing the interpretation of Western values upon societies which are very different from those of the West. This balance (or perhaps more accurately lack of balance) between the cultural values of a community with regard to disability and those of the state are described by Coleridge and Wahdat as the *CBR conflict zone*. They define the conflict zone as the interface of "local concepts of disability, culture, local social values, poverty and the nature of national CBR" and suggest that the CBR planner needs to be creative in order to manage potential conflicts and deliver a culturally appropriate CBR rather than standard "packaged service"(Coleridge 1998: 9).

REHABILITATION AND THE REHABILITATION PROFESSIONALS

Despite changes in attitudes towards people with disabilities, despite a much greater understanding of the discriminatory practices towards disabled people and greater respect for differences, most parents, on learning that their child has an impairment which will lead to a disability, look for a cure. This search for a cure, with all the financial, emotional and time resources which that involves in the early months and perhaps years of a disabled child's life, is perhaps more marked in the South. Estimates of how much ill affordable family income is spent upon a cure (using traditional and Western medicine) are hard to come by in the published literature but observation and practical experience suggest it is huge. In both the West and the South many parents' first construct of rehabilitation is to consider a medical cure. Sadly, many medical professionals condone this practice, taking considerable fees to see a disabled child with the parents knowing that there is little/no rehabilitation service and that all they can do is provide an (often inadequate) medical label for the condition which the parents know to be disabling for their child.

CBR is delivered by at least two, if not three, levels of service; a grass roots (often home based) programme, central CBR resources (perhaps with training facilities, workshops etc.) and therapists and others to whom referrals are made. It is important to recognise that this secondary referral system is an integrated part of most CBR programmes. The question arises as to whether therapy education prepares therapists for CBR work. The majority of therapy services provided in the West have developed from the medical model, people with disabilities are *referred* for assessment and, if appropriate, they are *treated* by professional therapists. Therapy delivered by a medical model is characterised by features such as:

- services being offered *for* or *to* people with a disability,
- the term *patient* is used to refer to healthy people who have a disability,
- services are provided *for patients*,
- the onus for change is with the *patient*.

The use of such vocabulary reflects a belief that it is the professional who holds the knowledge of what is best. Knowledge is seen as power ensuring professional control and as power in interprofessional rivalry, in the battle for resources and in salary hierarchies. In the early 1980s, in the U.K., pressure from disabled people raised an awareness of a social model of services where the disabled person's needs are central rather than professional practice directed at that person's impairment. Morris (1991) and Swain et al. (1993) review this issue. However, fifteen years after the beginning of this debate in the U.K. it is still primarily the professionals who arrange service delivery for disabled people in the U.K.

Student therapists in the South work hard to be awarded a scholarship to follow a degree course in North America, Europe or Australia or they have been dynamic professional leaders who have established a training course (often in the face of great fiscal and medical opposition) in their home country. In either situation the reality is that students in the South are attending courses where they are exposed to professional training and practice which may have been appropriate when the medical model reigned supreme in the North. Current training questions whether this provides appropriate professional training for social models which accommodate community care needs for any student, from North or South. If training to which overseas students are exposed in the North is inappropriate it is doubly so in their own home settings. Course directors in the South, anxious to maintain equality with courses in the North, veer away from innovative training in case it affects the international standing of their course. They too are then shackled to a training which neither prepares therapists for the realities of new working practices, of Community Care in the North, nor to community based working practices of the South. What often happens is that newly trained therapists in the South find difficulty in adapting their new skills to community based service and end up in the relative safety of private practice where they can use their (inappropriate) professional skills.

In order to be effective in a CBR setting therapists have to:

- be prepared to *give up* their exclusive rights to knowledge about impairments to a cadre of workers without professional expertise,
- be able to work as trainers and to support CBR workers,
- develop referral patterns of support for these CBR workers,
- continue to listen to DP and relate to disabilities rather than the impairments as a basis for intervention,
- be innovative in service planning.

These are tasks for which young therapists are often ill prepared and as a consequence they are often accused of lack of cooperation with CBR programmes. Working with colleagues in Brazil who train therapists has been an interesting exercise. There is a spoken (and genuine) wish by this group to move therapy services out of clinics and into the community. However they find it very difficult to give up their status and position as *the expert* and continue with training which they know to be inappropriate. For example, a follow up of deaf children 12 months after full audiological assessment, showed that only 4 out of 160 had received hearing aids, yet the group continue to train their students to undertake full audiological assessment rather than more creative assessment and training of the mothers in a society where hearing aids are clearly seldom available.

Colleagues in South Africa have taken the lead in the training of coworkers for an alternative form of service delivery through CBR (Bortz 1992). From this base therapists in South Africa have seen the need to cooperate with CBR, to become involved in training of CBR workers as a way of improving access to therapy services for all the population and not to restrict their services only to those who can access central, urban centres (Lorenzo 1995). In the Philippines too, innovations have been made in the education of therapists. All undergraduate therapy students at the University of Manila (OT, Physio and SLT) undertake a long placement in a rural CBR programme, thus ensuring that all therapists have at least an understanding of other ways of working with disabled people (Magallona/Wirz 1994). If we support improved access to services for the vast majority of people with disabilities in the South by understanding the aims of CBR and supporting them, we should not continue to provide professional training for students from the South which concentrates upon the needs of the very small minority.

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WESTERN(ISED) PERSONNEL FROM THE PRACTICE OF REHABILITATION PROJECTS VERSUS LOCAL CULTURES

Harry Finkenflügel

INTRODUCTION

This paper discusses *Western(ised) personnel from the practice of Rehabilitation Projects versus Indigenous/Local Culture*. The issue is narrowed down to *the role of Western(ised) personnel versus local personnel in rehabilitation projects*. In the author's opinion *development co-operation* in rehabilitation is first of all about *manpower development* or, in other words, *development of human capital*. The *aim* is not to build institutions, to set up an outreach system, to provide sewing machines for an income generation project, to send wheelchairs, or to make pre-fabricated prostheses available. All this might help to (re)gain abilities but living with a disability is, first of all – and like anything else in life – a learning and training process.

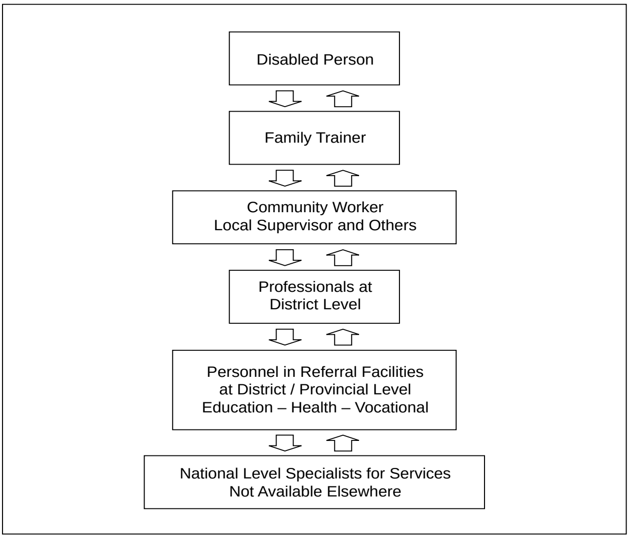
When discussing people as *human capital* people are seen as individuals with abilities and potentials, expectations and aspirations. People are not seen as instruments that can be used to reach goals that are not part of their own life. This applies of course to people with and without disabilities. What people do, what they want to do and what they want to learn is related to their expectations of life and their perceived role in their own family and community. The starting point of this paper is personnel as the service providers but our frame of reference is always the client: the person with a disability who seeks assistance. The client is part of the local culture. The rehabilitation worker might be or might not be part of this local culture. Both situations create opportunities and threats. At this point it is good to realise that there is no unambiguous definition or description of any local culture. People within one community most likely share some values and morals but will differ on others. Also communities are often stratified along family lines or traditional roles. A rehabilitation worker and a client from the same community might have the same understanding of the cause of the disability, the need for assistance and the perspectives but it is also quite possible that they hold different views.

Before working out a *S*trengths, *W*eaknesses, *O*pportunities and *T*hreats (SWOT) analysis of Western(ised) and local personnel the different cadres in the rehabilitation process are outlined. The author's experience is with education and rehabilitation projects in Zimbabwe, Malawi and, of course, the Netherlands. Examples will be mainly from these countries. It is assumed that the readers have a basic understanding of the Community-Based Rehabilitation (CBR) model. In this paper the CBR model will not be explicitly discussed but will be part of the discussion on the role of rehabilitation workers. Instead of sticking to a label like CBR the phrase *rehabilitation process* is used here to indicate that it is a dynamic notion, not limited to one type of service provision.

PEOPLE INVOLVED IN THE REHABILITATION PROCESS

The rehabiltation process cannot be described as a therapeutic intervention of a trainer and a person with a disability. Such an approach is far too simple. The rehabilitation process is a learning process which involves a complete client system (including the family and community) and a professional system. A large part of this learning process happens when the client is engaged in daily situations and happens without the intervention of professionals. Direct client-trainer intervention might be needed to start a new phase in the learning process or to correct the learning process. Guiding the people who are part of this learning process or changing the living environment are in most cases far more effective than direct intervention. Helander (1993) distinguishes six levels in the CBR delivery system (table 1). This model can help in discussing the role of (professional) rehabilitation workers.

Table 1: CBR Delivery System (Helander 1993)



In this article the focus is on the *Professionals at District Level*, *Personnel in Referral Centres* and the *National Level Specialists*. The Community Worker (CW) or Local Supervisor (LS) is, by definition, a member of the community. She/he might be chosen by the community, assigned by community leaders or approached by programme co-ordinators. Often these CWs are already involved in other health or education programmes (e.g. as Village Community Workers, Red Cross volunteers or pre-school teachers), are part of an organisation and easy to contact. Although these CWs sometimes get some kind of incentives (soap, food, clothes) or a part-time salary for their community work they are considered volunteers and non-professionals.

Professionals at District Level

The professional at district level is a formally trained professional. He or she might be a nurse, a social worker or a teacher with a few months additional training or a rehabilitation assistant or officer with at least twelve months' training. The need and the role of this cadre has been questioned and appears to fit into public service structures with great difficulty. These professionals may have different professional backgrounds, e.g. in medical rehabilitation, vocational rehabilitation, special education or social work. In practice it will be the aims and objectives of the programme, rather than the needs of people with disabilities, that determine what type of education is required.

In Zimbabwe the Ministry of Health started a *rehabilitation technicians training school*. Initially the rehabilitation technicians were seen as an affordable answer to the needs of the many people with disabilities. It was also presented as a short-term solution because in the long run enough physiotherapists and occupational therapists would be trained to attend to people with disabilities. By now this school has more than 200 graduates, a few dozen coming from other African countries. Most of them are working in district hospitals and are involved with community rehabilitation projects. It is important to note that these rehabilitation technicians do have a specific role in the practice of decentralisation of health (including rehabilitation) services in Zimbabwe. This, originally temporary, cadre has become an essential part of the health system (Hanekom 1983; Finkenflügel 1991; Mpala 1998).

McLaren (1986) proposes a four-tiered rehabilitation delivery system for rural health services in KwaZulu, South Africa. At the rural level paraprofessional workers (rehabilitation therapists), recruited from their own area, work under the supervision of professional therapists. Also from South Africa is a study by Dolan et al. (1995) on the training of Community Rehabilitation Workers who, after a two-year training, are entirely community based and will use the district hospital as a referral centre and resource base.

Cornielje and Ferrinho (1995) and Deetlefs (1995) described the training and practical experiences of Community Rehabilitation Facilitators (CRFs). In this two-year training programme rehabilitation is approached as part of community development. Training focuses on the enhancement of knowledge and skills in community development and contrasts with medically orientated training. In Malawi, MAP (Malawi Against Polio) trains MAP-assistants for their outreach rehabilitation services (Chipofya 1993). Other countries have set up different training paths; sometimes one-offs, sometimes on a regular basis.

Personnel in Referral Facilities at District/Provincial Level

In the WHO-CBR model professionals in referral centres at district/provincial levels are working in the fields of education, health or vocational training. These professionals train professionals at district level and will provide diagnostic and rehabilitation services for people with disabilities referred to them. CBR-programmes are often run by professionals like nurses, physiotherapists, occupational therapists, social workers, and vocational trainers. All these professionals have, on the basis of their own background, developed a broader view of rehabilitation through experience and study. Some have been able to attend additional training in CBR; for example the CBR training course of the Institute of Child Health in Britain (Guthrie 1986). There is probably no professional education that is perfectly suitable as a basis for becoming a CBR-trainer. (Most likely there is also no professional training in the field of education, health, or vocational training that is a contra-indication to becoming a CBR-trainer.)

Mendis, a physiotherapist by training and involved in CBR for two decades, commented on the role of the physiotherapist in primary health care in developing countries. She argued that there is a "need to reconceptualise our role in rehabilitation along the lines of the new approaches so that we are capable of guiding primary health workers, the community, the family and the disabled in the total rehabilitation process" (Mendis 1982: 34). The question *what makes somebody a good trainer* is not easy to answer. McAllister (1989) writes about her personal experiences as a physiotherapist working in Zimbabwe. She appeared to be impressed by what is, and can be, achieved but points out that expatriate therapists encounter many frustrations and limitations in their work as it involves many administrative duties. She continues, "Initially, it is essential to stand back, observe and learn about the people" (McAllister 1989: 7). I'm sure this is a quality that applies to every professional in CBR. It has been outlined already that it is not only medically trained professionals that get involved in CBR. Zhoya (1986) presents a personal view of the one year Certificate Course in Rehabilitation at the school of Social Work.

National Level Specialists for Services Not Available Elsewhere

Specialists at national level are qualified in the training of clients with rare conditions or are seen as extremely skilled in the intervention with clients with specific disabilities. Their role is to function as a referral centre and to collect and disseminate knowledge about the training of these clients. Also at national level we find training schools for professional rehabilitation workers. These training schools can be part of a university or polytechnic and are often linked to a hospital, rehabilitation centre or a special school.

Local and Western(ised) personnel can work at all professional levels. Some donor-organisations have made it a policy to support people at grassroots-level and send trainers to work directly with the people in the community. Other donor-organisations support the training and back-up of local personnel and station their trainers at provincial and national levels.

Before proceeding to an analysis of strengths, weaknesses, opportunities and threats as regards the different professionals it is important to realise that local personnel in rehabilitation often hold a double position. They are familiar with more traditional beliefs about disability and know the social context of families and communities and the roles of the people. Their education is modelled upon the same lines as in Europe. They are very often even trained by Western(ised) personnel, either by having had their education abroad (United Kingdom, Canada, the former Soviet Union, Germany etc.) or being taught at home by expatriates from Europe or North America. Local personnel is trained with Western concepts of health, disability, equity and citizenship. From the author's experience in Zimbabwe it is noted that most trainees use both reference frames and try to make them supplemental to each other. This has also been described by Barbee (1986), who talks about a dialectic tension between traditional beliefs and acquired beliefs.

ANALYSIS OF STRENGTHS, WEAKNESSES, OPPORTUNITIES AND THREATS (SWOT) OF WESTERN(ISED) AND LOCAL PERSONNEL IN REHABILITATION PROJECTS

The *s*trengths, *w*eaknesses, *o*pportunities and *t*hreats (SWOT) can be visualised using a simple quadrant.

Table 2: SWOT-Quadrant

Strengths	Weaknesses
Opportunities	Threats

Each quarter can be completed for both Western(ised) and local personnel and the results can be used for discussion and analysis. Strengths create opportunities and weaknesses hold threats. A step further, it can be argued that *strengths* can also imply threats (e.g. a highly skilled professional who excludes others from treating some clients) and that weaknesses can become opportunities (e.g. ignorance, unprejudiced observations and study can lead to unknown and unusual but successful interventions). A SWOT analysis can be most helpful to reflect on our roles and to make pitfalls visible. Western(ised) rehabilitation workers might easily consider themselves as highly skilled rehabilitation workers with a big rucksack of practical experience and scientifically-based knowledge. Although this paper is not the right forum to discuss this supposedly scientifically-based knowledge it is useful to point out that recent studies in Europe and North America teach us that there is hardly any scientific basis for the interventions in physiotherapy, occupational therapy and speech therapy. This leaves us with a lot of practical experience gained in Western hospitals, institutions and private practices. As for those trained in Europe, community work is not part of the training and nor is teaching and coaching. In this SWOT analysis it should be discussed what our skills are worth in the context of a developing country. It might seem obvious that a physiotherapist specialised in problems of the mandibular joint might be of great value in industrialised countries but will not be considered a priority in developing countries (although there are also people with mandibular joint problems). But what about a physiotherapist or special teacher with no specialist skills? Is he any better than a local rehabilitation worker with the same skills or can he even learn from local rehabilitation workers with specialists skills? If so, what is he doing in a developing country? In the workshop on *Local Concepts and Beliefs about Disability in Different Cultures* in Bonn (May 1998) the participants came up with a lot of suggestions. These suggestions are summarised in the following two quadrants.

Table 3: Western(ised) Personnel

1. Strengths	**2. Weaknesses**
– full professional education including post-graduate courses – broad clinical experience – access to professional organisations / networks – access to foreign donor funds – good understanding of scientific approaches to health issues	– professional education aimed at people living in industrialised countries – lack of community experience – not familiar with local organisations / networks – no access to local resources – limited understanding of traditional beliefs and community-oriented systems of health care
3. Opportunities	**4. Threats**
– increase knowledge about impairments, disabilities and training programmes – share clinical experiences – involve professional and donor organisations in the development of rehabilitation services in the host country – offer a different understanding of disability to decrease stigma in some types of disabilities	– offering supply-generated rehabilitation services – offering culture-alien rehabilitation services – medicalising or educationalising disability issues – shift of responsibility from community to professional services – create dependency on western type of health care

Table 4: Local Personnel

1. Strengths	**2. Weaknesses**
– education based on local needs / circumstances – ample community experience – familiar with local organisations / networks – access to local resources – understanding of traditional beliefs and community-oriented systems of health care	– poor access to post-graduate courses – limited affiliation with (national and international) professional organisations – limited access to international resources
3. Opportunities	**4. Threats**
– offer needs-generated rehabilitation services – involve local political health, education and other organisations – to deal with dialectic tension between traditional and acquired beliefs (to get the best out of the two approaches)	– knowledge and skills stagnate or deteriorate – none or poor testing of quality of work by – colleagues – no financial resources to back up intervention and gain credibility – adopting western concepts to increase status – presenting local knowledge as inferior to western-based knowledge

The participants pointed out that disability and handicap are tightly linked with local beliefs and local living circumstances. The applicability of standard Western interventions and solutions is limited. Locally trained personnel will more easily understand these local beliefs and will adapt their interventions to the local circumstances. Local personnel is also not part of the supposedly rich, four-wheel driven services provided by foreign NGOs and expatriates and are so less troubled by demands from people with a disability for relief, money or compensation. The SWOT-analysis reveals a lot of differences between Western(ised) and local personnel but by listing these, and by enlarging the differences, it looks as if both are being made into caricatures. One can easily argue that some local personnel is highly qualified and has a leading role in international organisations and with international NGOs. It can also be argued that knowledge about local culture and traditional beliefs has been collected by (Western) anthropologists and is being integrated by Western(ised) personnel in rehabilitation programmes. Despite all this, the SWOT quadrants are helpful and will give us tools to overcome the difficulties; the weaknesses and threats.

ARE THERE WAYS TO OVERCOME THESE DIFFICULTIES?

On the basis of the SWOT-analysis it is as legitimate to answer the above question with *yes* as it is to say *no*. For the local rehabilitation worker the challenge appears to be how to integrate traditional beliefs about disability and knowledge about society with the Western perception of these. If she/he is not able or willing to accept the ideas of her/his (Western) teachers and (international) colleagues she/he will bring professional isolation upon her or himself. The Western, scientific approach to health issues is the dominant approach in this epoch. On the basis of this approach people involved in rehabilitation set their priorities for clinical work and research and allocate funds.

We now see a co-operation between Western, scientific, health care workers and some traditional health workers, e.g. traditional healers and traditional birth attendants. This co-operation is based on the presence and availability of traditional healers and birth attendants and their role in community health. Such co-operation programmes are not known to exist in rehabilitation, most likely because *disability* has not been recognised as a bounded, well defined and separate issue. Traditional handling of people with disabilities is scarcely documented and/or often not accessible to Western, and even local, rehabilitation personnel.

For the Western(ised) rehabilitation worker the question is to what extent he/she is able to adapt to local circumstances and to the local needs. Overcoming the difficulties is not the same as eradicating the differences. It might not even be realistic or wise to strive to overcome the differences. A better strategy for the Western(ised) personnel is to recognise and admit the differences and work out how she/he can handle these differences and how these can be integrated. The differences between Western(ised) and local personnel in the practice of rehabilitation are most visible in the direct intervention between the person with a disability and the trainer or in the interaction between a trainee rehabilitation worker and a Western(ised) teacher. In the author's opinion we should not aim at changing beliefs and attitudes related to disability. What needs to be done is to present a different framework – alongside their own frame of thinking – and to show that disability is not irreversible and that the person with a disability is able to learn. The author's experience is that children might be seen as victims of disability but are not held responsible for the cause. Caregiver and child were accessible for training and the family would try to resolve the *why-issue* separately from it. On the other hand some people who had had a stroke were not motivated to have training because they believed they were responsible for the stroke themselves and their first priority was to resolve the family matters that caused the stroke. This point of view might sometimes feel inhuman. It is hard to see people who could benefit from rehabilitation but are not accessible to us suffer. And it is difficult not to solve daily and short-term problems because rehabilitation workers have committed themselves to training and coaching and expect results in the longer term.

A local counterpart is indispensable for every Western(ised) rehabilitation worker. If it is not possible to work with a colleague then one should team up with somebody who knows the local situation and the people. The first priority of Western(ised) rehabilitation personnel is to train, coach and support local rehabilitation personnel. Too often Western(ised) rehabilitation workers work intensively with people with a disability for a period of two or three years in a remote area, district or referral hospital and realise by the end of their contract that the only way to carry on with the work is to bring in another Western(ised) rehabilitation worker. This might be quite acceptable if people at other levels (i.e. community and district level) have been trained and if it is embedded in manpower development planning that plans for deployment of local personnel in a reasonable period.

Rehabilitation is not a matter of life or death. It is acknowledged that early intervention gives better results but there is no excuse for a Western(ised) rehabilitation worker if she/he does not involve a local colleague, counterpart, nurse, teacher, volunteer or family member. This all means that the intervention of the Western(ised) rehabilitation worker should not aim at the person with a disability but at the people who are involved in the training of this person with a disability. The person with a disability discusses her/his problems with a local rehabilitation worker. They share the same frame of thinking or at least they are able to create a basis of understanding. The indigenous/local rehabilitation worker is the key person when it comes to linking traditional views with the Western approach. And if we want to understand the local colleague we should try to be open-minded. Ignorance and questions work better than explaining how the world should be. One of the best ways to learn about traditional beliefs and traditional handling of people with disabilities is to start discussions with trainee rehabilitation workers. They have been introduced to a Western scientific approach to disability but also still have their roots in their own community. In Zimbabwe the students were very willing to discuss our and their views on the causes of disability. For example: a virus as the causal agent for polio was acceptable but not that one child contracts polio and another child in the same village, using the same water and sanitation facilities, doesn't. (There is always a danger that people who become educated and start earning money turn their back on their own background, regarding this as backward and simple. This is not typical for developing countries but it disqualifies these people from being a key person acting as intermediary between the local community and Western approaches.)

As a teacher the author found it difficult that students started using status symbols like a white jacket and stethoscope. Symbols that most of us Western(ised) personnel have abandoned in non-clinical settings. But maybe we should give them the same credit as we have advocated for people with disabilities and their communities. If this is within their frame of thinking it is to be approved and tested by others within the same frame of thinking.

In a chapter with the title *to overcome difficulties* it is tempting to end with do's and don'ts. But with regard to this subject *the ten golden rules* should be avoided. Maybe except one: *development co-operation is a continuous learning process and we should try to keep this process going.*

Without pretending to be complete the paper, including the input of the participants of the workshop, can be summarised in a few lines.

- There is not one concept of rehabilitation, nor is there a blueprint. Realise that any concept is a product of a culture that encompasses much more than rehabilitation or disability issues.
- Make sure any intervention is within the frame of thinking of the other. Work together with local personnel who share or understand the traditional beliefs of the people with disabilities.
- Training and education are more sustainable than direct intervention.
- Ignorance and questions are better tools than persuasive force.

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DIFFERING PERCEPTIONS OF THE PRINCIPLE OF PARENT PARTICIPATION: IMPLICATIONS FOR ASIAN FAMILIES OF CHILDREN WITH DISABILITIES

Maya Kalyanpur

This article discusses some of the problems associated with the transfer of special education models and concepts from developed to developing countries, with specific reference to the concept of parent participation. It describes the Western interpretation and the underlying values of the concept, and analyzes the implication of this culturally-specific understanding for Asian families of children with disabilities. I use the Western concept as a point of reference because it provides a framework to better explain and understand non-Western concepts. However, there are two caveats I would like to make before I proceed. One is that when making these comparisons, I do not wish to imply that one way is superior to another, but merely to identify the differences and increase awareness of these differences. Another is that most Western concepts emerge from Western rationalism. As a result, because alternative perspectives are often the opposite of the Western ones, sometimes they can be misunderstood as being irrational. We need to understand that people behave in certain ways that are rational to them. Merely because the behavior is different does not make it irrational.

If we identify the values and taken-for-granted beliefs that are imbedded in special education and rehabilitation policy and practice in Western countries, we can begin to understand why it becomes problematic when we transfer this knowledge to developing countries where other values may prevail and are taken for granted. The three predominant values that are imbedded in the Western concepts of parent participation in special education policy are equity, choice, and individualism.

EQUITY

Equity is a cornerstone Western value. It is the basis on which disability rights movements and the essential premise of special education – the belief that all children, including children with disabilities, have the same right to an education – have emerged. For instance, special education itself is an equity measure. The value of equity is also imbedded in the principle of normalization: the intention is to provide the same opportunities and quality of life outcomes that are available to non-disabled people to a person with disabilities. So too with the principle of parent participation. In the U.S., for instance, special education law entitles parents of children with disabilities to certain rights: they have the right to participate in the decision-making about their child's education, to be informed of any changes in placement, and should they disagree with a decision, under procedural due process, they have the right to protest. On the assumption that parents have knowledge about their child as important as the professionals' knowledge, this principle provides parents with opportunities to partner with professionals.

Problems arise when this equity-based principle is imported into developing countries where there may be no expectation of parent-professional equality. Many Asian families may believe instead in the fundamental tenet of "the value-inequality of human beings, by reason of birth, caste, skin pigmentation, economic and social status" (Miles 1981: 7). For instance, Wong (1989) notes that, among some Chinese families, people are assumed to have different capacities owing to different backgrounds (such as education) and characteristics (such as age); it is therefore accepted that some people should dominate over others because of their status. Similarly, among many Indian (Mohan 1992) and Korean (Song-Kim 1992) families, since social roles and duties are ascribed, the status of various family members is also predetermined in terms of a hierarchical order. Thus, elders have high status, men have higher status than women, and children assert their authority according to birth order. Indeed as Schweder, Mahapatra and Miller (1990) note, to many Hindu families, "the justice of received differences and inequalities, ... (the) asymmetrical interdependencies in nature (for example, parent-child) and the vulnerabilities and differential rationalities of social actors (are) universal truths" (p. 160). To prevent the abuse of power in hierarchical structures, there is the expectation that those in more privileged positions will recognize their obligations towards the less privileged, a sort of *noblesse oblige* also known as *dharma* or duty in India (Fishlock, 1983; Kalyanpur, 1996) or *li* or rules of propriety in

China (Wong 1989; Chung 1992). By the same standard, professionals, by virtue of their higher status, have a similar duty towards protecting and ensuring their clients' well-being. This understanding conflicts dramatically with the idea of individual responsibility that places the onus for partnership on parents.

The rigidly hierarchical societies in many Asian countries preclude the possibility of partnerships on an equal basis; indeed, both parents and professionals are culturally conditioned to maintain a differential status in favor of professionals. In my own research with low-income families of children with disabilities in India, I found this to be a significant issue (Kalyanpur 1994). The professionals at the school the children with disabilities attended wanted to include parents because they had heard from the West of the concept of parent participation. At the same time, however, they lacked the cultural basis for establishing equitable relationships and did not perceive the parents as equal partners. The resultant *parent participation* consisted primarily of workshops conducted by the professionals, who determined the topics, and interspersed themselves among the parents to *keep them from chattering to each other*. The parents continued in their role as recipients of information and their opinion on their child or the services was never sought.

The taken-for-granted premise of equality imbedded in the concept of parent participation in the West was lost in the transfer to a country where the milieu lacked any emphasis on rights and equality. Since parent participation in the education decision-making process is a desirable outcome because parents' needs are better met and children are better served, we must identify the values that do prevail in the importing culture and use these values as a frame of reference to create a more equitable level of parent involvement. For instance, in India, a prevailing culture of duties or *dharma* provides a more meaningful metaphor in which to couch the idea: by presenting the concept of parent participation to Indian professionals in terms of professional responsibility or duty to parents, it is more likely that collaborative, if not equitable, relationships will develop, where parental input into the decision-making is sought (Kalyanpur 1996).

CHOICE

Choice is another cornerstone value imbedded in the principle of parent participation. For instance, in many developed countries like the U.S. and Germany, parents may choose to participate in the decision-making process for their child's education and placement and decide whether they would like their child to attend a full inclusion or a separate school. This emphasis on parental choice emerges from the high regard placed on the value within society, and the belief that people must be allowed to have choices when selecting their lifestyle, career, life partner, place of residence, etc. This belief also underpins the concept of self-determination for people with disabilities, whereby they may have opportunities to make choices similar to those available to non-disabled people. Indeed, so highly regarded is the value of choice that equity-based legislation seeks to ensure that individuals who possess a trait – an *immutable characteristic* – which could reduce their chances for making choices toward the pursuit of happiness will not be denied these opportunities. However, if we transfer the concepts of parental choice or self-determination to a culture where there is no context for choice, the situation becomes problematic. For instance, in many Asian countries, families may not regard the value of individual choice as highly, and may severely proscribe personal choices on many aspects (Chung 1992; Mohan 1992). Some societies do not allow individuals a choice in the matter of religion (Ross-Sheriff 1992), while some families continue to restrict their adolescent children in the number of choices they may make about making friends, choosing an occupation, and selecting a life partner (Mohan 1992). By the same token, a trait, such as gender, that in one culture may be perceived as an immutable characteristic justifying equity-based legislation, may in another culture be interpreted as justifying specific acts of discrimination. For instance, among some Indian (Mohan 1992), Muslim (Ross-Sheriff 1992) and Chinese (Chung 1992) families, the belief that a woman need not work outside the home or have a career often precludes girls from receiving an education or pursuing any academic goals more ambitious than an elementary schooling.

In cultures where personal choice is not a highly regarded value, parents do not expect to have choices about services; nor would they expect that their child with disabilities learn or be allowed to make choices on matters that even their non-disabled children would not make. Further, parents would not assume they or their children had the right to demand such choices. In India, for instance, this is one of the reasons for the lack of grassroots support for a disability rights movement.

INDIVIDUALISM

The high value placed on the right to freedom of choice in Western countries is related to the emphasis on the individual and the belief that the individual, not society, comes first. This individualistic belief provides the underpinning for the idea that all citizens have rights that are protected under the law. In many Western countries, parents of children with disabilities have rights specific to their child's education. Implicit in this is the idea that people are responsible for ensuring their own protection, from which the principle of due process or the right to protest emerges. Due process is a process of dispute resolution that involves formal legal mechanisms; the process can be initiated by ordinary citizens and is not imposed from the top down (Turnbull/Turnbull 1998). Friedman (1996) has argued that the tendency to sue is a structural and cultural feature of American society that emerges from modern individualism; as he states, "it would be hard to imagine much litigation among people who truly believe that it is wrong to make a fuss, or who value harmony and compromise above most other values" (Friedman 1996: 58).

Similarly, the concept of an individualized education required by law in many Western countries provides a focus on the individual. Since the purpose of education is to provide students with the skills they would need to acquire a job and become independent, productive adults (Margonis 1992), the underlying assumption in this principle of individualization is that a meaningful education for children with disabilities is one that maximizes their potential towards the ultimate goal of independence: open, competitive employment (Powers/Singer/Sowers: 1996). Such a high value is placed on individuals becoming self-reliant and responsible for making their own life choices, that these outcomes are a major part of most special education and rehabilitation plans for people with disabilities. However, these concepts of individualism may be antithetical to the beliefs of many Asian families with children with disabilities, which may lead to some dissonance when planning an appropriate education. For one, some families may traditionally subscribe to a concept of self where individual identity cannot be separated from the group, believing that, indeed, it is a product of the group (Brady/Anderson 1983; Ross-Sheriff 1992; Wong 1989). Since individual needs are subservient to those of the community, a "culture of duties" (Chung 1992) prevails where individuals have ascribed social responsibilities (Schweder/Mahapatra/Miller 1990). For instance, Wong (1989) notes that the values of participatory democracy and individual rights conflict with traditional Chinese values of propriety and individual duties:

> The Chinese conception of the individual, in contrast to the Kantian tradition, is not one of an abstract entity. Here, roles and statuses determine one's dignity; differences in abilities are believed to be relevant in evaluating one's worth; one's behaviors are very much constrained by social identity and the related obligations it imposes. As such, it is not difficult to understand why the Western conceptions of *rights* and *equality* are so foreign to the Chinese. (p. 97)

In such a context, families may be both unfamiliar and uncomfortable with the prevailing *culture of rights* on which the concept of parent participation is based. Studies indicate that families that have recently immigrated to the West from countries where schooling was not the norm for children are most likely to be unaware of their child's right to education, particularly in cases where the child has a disability, or of their right to protest if their child's rights are violated (Dentler/Hafner 1997). Further, even after having been made aware of their rights, they may be unable to assume the level of assertiveness needed for claiming them. For instance, the organizer of a support group of immigrant Vietnamese families of children with disabilities in the U.S. described a problem he faced in helping the families access services:

> People are afraid of asking for favors ... I try to show them, to explain to them that they have the right to ask for the services and they are not asking for a favor. (N. Chu, personal communication, April 9, 1997)

CONCLUSION

This article analyzed how the values of equity, choice and individualism subtly frame the Western interpretation of the principle of parent participation in special education. When this culturally-specific concept is transferred to other cultures, families of children with disabilities are placed at a disadvantage. In a climate of value-inequity, parents may persist in deferring to professionals as figures of authority. In a context that lacks choices, parents may unquestioningly accept the service options given them and circumscribe their children's life choices. In a culture of duties, parents may not demand their rights or advocate for their child, gratefully believing instead that any service their child receives is a *favor*. By the same token, professionals may not seek parents' input about their child's education nor attempt to develop collaborative relationships. As a result, the benefits of services may be considerably lessened, adversely affecting both parents and children with disabilities.

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FORMAL HANDLING ROUTINES. CHILD REARING PRACTICES IN JAMAICA AND THEIR RELEVANCE TO REHABILITATION WORK

Annette van der Putten

THE FORMAL HANDLING ROUTINE

In Jamaica exercising and massaging new-born babies immediately after and during bathing seems to be a traditional part of child rearing practices. Hopkins (1976) introduced the term *formal handling routines* for these practices. It was defined as:

> ... routines in which the caregiver acts in a pedagogical manner and implies a series of physical exercises and massage with infants from the first days of life onwards. (p. 17)

A study was carried out in Jamaica in order to:
- determine if the formal handling routines are still in use in Jamaica and to give a description of the use and content of the formal handling routine.
- establish differences in the use of the formal handling routine between caregivers of children with and without a disability.

The fieldwork of this study was carried out in a rural area in Jamaica. 52 caregivers were interviewed: 28 mothers and grandmothers of children with a disability and 24 mothers of children without a disability. The caregivers were interviewed about the reasons for carrying out the routine, the different sections, the age of starting the routine, the frequency, duration and continuation of the routine. Caregivers of the children with a disability were asked additional questions about the responses of the child during the exercises and massage and if and how the caregivers modified the routine to these responses. The mothers were also asked to demonstrate the complete routine. Some of them gave permission to tape it on video. All 52 caregivers carried out the formal handling routine fully or partly. Most of the caregivers were initially hesitant to talk about it but eventually responded enthusiastically. The main reasons for carrying out the formal handling routine are "to help the child to grow", "because it is tradition", "to get or keep child flexible", "to test if the child is disabled" and "to give the child a better shape". The most frequent reason was that physical exercises will facilitate the child's development and growth and that the child will get stronger and grow healthier. "When I got my first child I was living with my mother and she told me to do the exercises. She explained that exercises are good for babies because they grow faster and healthier." Caregivers mentioned that they were not aware of carrying out a routine, they just did it because their mother did. "I shaped my child right after he was born. God has already shaped them how he wants but it is tradition so I did it." Caregivers also mentioned that with the exercises you can "keep or get your child's body flexible". "For his joints to stretch freely, so he doesn't get problems with walking and crawling." The routine also has been used as "a test to see if the child is disabled". With the exercises and stretching techniques, caregivers test the child's body and the responses. "Some children have slip joints; you can find out with exercises. Nurses are doing the same tests." The routine is also carried out to influence the physical appearance. The child will look stronger and develop better features; the exercises give the child "a better shape". "If you do not 'catch-up' the bottom they have no good shape." The routine is carried out during and immediately after bathing the child. Caregivers said that bathing the child in cold water that has stood overnight, possibly with soaked ashes, gives them more strength. The bathing water is sometimes thrown into the street to make the child walk quicker and faster. Caregivers of children with a disability, especially with spasm, mentioned that they sometimes bath the child in warm water to make it more relaxed.

The whole routine can be separated into different parts; sopping, stretching, active exercises, massage, shaping and catching-up. Each part of the formal handling routine has its own purpose and performance.

- *Sopping*: During bathing, the caregiver slaps the child's back, waist and joints with the bath water. One caregiver explained about leaves called *bush–bush*, which are put into the water. These soaked leaves are used to slap the child's joints to strengthen them. Another caregiver explained that giving the child some bath water to drink gives it more strength in the body. Caregivers gave several reasons for carrying out this part of the formal handling routine. The most frequent reason for sopping was to strengthen the back, joints and muscles. Other reasons for sopping were to get the child used to the water, to let the limbs grow faster and to get the child more active.
- *Stretching*: This part of the routine was done mostly after the child comes out of the water. Several joints, especially the elbows, knees

and hips, are stretched passively when the child is lying down on its back. Reasons for stretching are to help the child to move and walk quicker, make the joints move more freely and *straighten up* the child. Some specific stretching techniques were discussed frequently. The child's neck was stretched by lifting the child up by holding its head on both sides. The child's arms are stretched when the child is suspended by one or both arms. The legs are stretched by holding the child by one or both ankles and turning the child upside down. A *cartwheel* is often carried out. Some of the caregivers explained that when they had their first child they were living with their mother, and the grandmother carried out the formal handling routine. Later when the mother was more experienced in child care, she carried out the routine by herself with her other children.

- *Active exercises*: With the active exercises, the caregiver moves the limbs of the child while it is lying on its back, so in fact it is partly supported and provokes active movements. This part is carried out to strengthen the limbs and the body and to test if the child is all right. Caregivers of a child with a disability also used this part to get a stiff child more flexible. Extension of the legs was provoked by bouncing the child with the feet on the lap of the caregiver as preparation for walking.
- *Massage*: After bathing, when the child is dry, the caregiver rubs the child's skin, usually with olive oil. One caregiver of a child with eczema used some specific oil for his delicate skin. The main purpose of the massage was to protect the skin from sores *in* the joints, caregivers explained.
- *Shaping*: With shaping the mother attempts to mould several parts of the child's body in order to influence its physical appearance. In general, caregivers start shaping immediately after birth when the child is still *hot and soft*. This part of the routine is not only carried out during bathing but also during the day. Special attention is given to the nose. The flat nose is shaped to get it straight; this part is one of the most well known parts of the routine. The importance of a straight nose is explained by the following caregiver. "I shape his nose because my nose is straight, the child's father's nose is straight, so our child's nose has to become straight too. Because when it is not straight nobody believes that it is our child."
- *Catching-up*: This part does not really belong to the routine; it is not carried out during or immediately after bathing. It is included here because many of the caregivers mentioned it. When catching-up the caregiver makes the child sit and supports it with pillows. Caregivers

declared that catching up a girl starts at three months and a boy at four months. Caregivers believe that the back of a boy is longer and therefore weaker and needs more time to get stronger.

In general caregivers start bathing the child after the umbilical cord drops off (about ten days after birth), but start parts of the routine, like shaping, immediately after birth and other parts like catching-up later. Usually the child is bathed in the morning (6 am) and sometimes in the afternoon (4 pm) and so caregivers usually carry out the formal handling routine once or twice a day. Most of the caregivers did not know exactly how many minutes they spent carrying out the routine. They explained that carrying out the routine was something they are not aware of. The most frequent answer was "just a few minutes". Several reasons were mentioned for stopping carrying out the formal handling routine. In general, caregivers stopped the stretching and active exercises when the child was able to move around by itself. Some caregivers explained that the child was moving around when it started crawling; others said when the child starts walking. This means that the child is physically fit and is able to exercise itself. Another reasons to stop stretching was because the child was too big to manage it. After stopping stretching, active exercises and catching up, often the massage and sometimes sopping are continued.

Caregivers of children with disabilities started all parts of the routine at a later age than the caregivers of the children without disabilities. This difference was significant (p <.01) between the groups for sopping, stretching and active exercises. This can be illustrated by the following remarks given by caregivers of children with a disability. "I started the exercises when she was six months old. Before that age she couldn't do anything. When I started she improved. When she was nine months she was able to sit."

RESPONSES OF THE CHILD WITH A DISABILITY

Of the caregivers of children with a disability 25 (89 %) did notice during the routine that the child's responses were different from normal children. Two caregivers did not give an answer and one caregiver could not answer the question because she had no experience with another child but mentioned that she noticed while carrying out the routine that her child was very *floppy*. Caregivers of children with a disability did notice in general that their child was slow in his total development (motor, emotional and social) and small in size compared to other children. Some of the children with a disability did not respond like children without a disability, as one of the caregivers explained as follows: “He was slow, he didn’t smile and didn’t move around like other children. He couldn’t stretch out his foot and was not able to balance himself.” Some caregivers also noticed that the child’s joints were stiff, or just that the child was completely floppy and did not like the routine. “My healthy baby co-operates more, Ramon is more stiff and doesn’t come when you call him compared with my healthy child,” “My child was floppy, had a very soft skin and the joints were very flexible. The child didn’t like the exercises at all, she was very afraid when I stretched her.” “He cried when you stretched him. He was not walking, he was on his belly for five years so I had a lot to do with this boy.” Of these 25 caregivers, 81 percent changed the routine because of the child’s reaction. They changed the duration, frequency, continuation and content.

It appears that caregivers of children with a disability spent more time carrying out the routine. Some of them spent 15 or 20 minutes while caregivers of children without a disability usually spent just a few minutes carrying out the whole routine. “I do it longer and shape and massage her back more and catch her up with something stiff instead of soft materials.” Most caregivers of children without a disability carry out the routine once a day. Caregivers of children with a disability seem to carry out the routine more frequently; *twice a day* or during the day. “In the beginning he was small and slow so I found out that there was a problem; I did more exercises with him during the day without bathing. When he finally started to walk he walked tiptoe and I continued to massage and stretch him until he was able to walk properly.” The main reason to stop carrying out the stretching and active exercises was that the child was able to move around by itself (when the child starts crawling or starts walking). Caregivers of children with a disability continued carrying out the routine longer because the development was slower or they were never able to move around independently. Some of the caregivers were still doing exercises when the child was four or five years old. “My child is five years old and I still carry out the exercises. Because her feet and knees are stiff I still massage and stretch her to keep her flexible. Sometimes I do it less because she is sick and you cannot move her so freely and I have to do it more carefully.” Depending on the type of disability, the child’s reaction and the way the disability occurs, the caregiver adjusted the way they carried out the routine. “When I found out that he was sick I didn’t turn him up and down anymore, I did everything more tender and gentle." "For a normal child it's good; with a disabled child you have to be more careful."

DISCUSSION

Results of this study showed that Jamaican caregivers carry out the formal handling routine completely or partly. The assumption that the continued use of the formal handling routine is dependent on whether the child is disabled or not is supported by the results of the current study. Caregivers noticed during the routine that *there was something wrong* with the child with a disability, adjusted the content of the routine to the child's responses and started at a later age than mothers of children without a disability. Hopkins and Westra (1988) suggested that Jamaican mothers were functioning as *intuitive neurologists* and that the routine can be used as *a diagnostic and therapeutic tool*. This is supported by the results of the current study. Caregivers seem to be very experienced in exercising their new-borns and in identifying problems in the early development of their babies. O'Toole (1989) mentioned that in parental involvement in rehabilitation programs for children with disabilities, overburdening the mother is a risk. One of his suggestions was to integrate the rehabilitation of the child into the daily routine. The current study shows that the formal handling routine is a part of child care that is integrated into the daily routine. The routine, along with the knowledge and experience, is a good starting point for early intervention and rehabilitation and the practice needs to be reinforced.

This study illustrates that we have to be modest when introducing Western scientific rehabilitation concepts into different cultures. Jamaican mothers have skills available that are part of their cultural inheritance and fit in with Western rehabilitation techniques. The frames of thinking overlap partly and this should be a starting point for further training. I am sure that in most countries people do have certain routines in handling children with a disability or in guiding adults with a disability. Also in the field of rehabilitation developing countries are not a white spot on the map. The reality is that people have been coping with all aspects of disability for many years. The challenge is to show that we take these efforts seriously and offer approaches that might be complementary to or even help to promote the traditional approaches. This should reinforce the learning process in such a way that people with disabilities and their families/communities can benefit from it.

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“NOTHING ABOUT US WITHOUT US.” CASE STUDIES OF SELF-HELP MOVEMENTS

MEETING WOMEN'S NEEDS. WOMEN AND GIRLS WITH DISABILITIES IN THE PRACTICE OF REHABILITATION PROJECTS

Jenny Kern

INTRODUCTION

The topic *Participation of Girls and Women with Disabilities in Rehabilitation Projects in Developing Countries* could fill an entire conference. And because of the growing critical awareness that the experience of disability for women and men differs, I am hopeful that meetings such as the one on *Local Concepts and Beliefs about Disability in Different Cultures* in Bonn, May 1998, will continue to examine the gender perspective. Rehabilitation must be examined within the larger social contexts that shape the lives of women with disabilities. Women with disabilities are women first. And they also have disabilities. For both, they are devalued by their societies. For those living in developing nations where health care, adequate nutrition, jobs, mobility equipment and many things people of the Western world take for granted are scarce, the difficulty of being a woman with disabilities is certainly compounded.

I begin with brief general descriptions of the status of women, people with disabilities and women with disabilities. Relying primarily on their descriptions, I then identify the barriers most women and girls with disabilities face in accessing rehabilitation services in the so-called Third World. Using the Whirlwind Network as a model to examine women's absence from *rehabilitation* projects I describe Whirlwind Women as a possible recipe for women's participation. I then describe the shifting models of both Community Based Rehabilitation, or CBR, and women in development projects and discuss disabled women's opportunity to participate in both with examples of potentially successful projects. Finally, I examine the emerging international movement of women with disabilities that is and will continue to be a critical antidote to the oppression of women with disabilities.

THE STATUS OF WOMEN: LESS THAN EQUAL

Regardless of the ways in which women experience their gender and despite the importance it has to them as individuals, the cultures and communities in which they live place their own values and expectations on the female gender. Notwithstanding huge shifts in many cultures, the social status of women remains, at the end of the 20th century, vastly inferior to that of men. They have far less power, money and influence than they should, considering that they number more than half of the world's population. Their work as tenders of the family and caregivers, when this is counted as work, is undervalued and unpaid. Their work outside the home is valued less than that of men, as well. In addition, they endure drastically high levels of poverty, illiteracy and violence because they are women. Gender based crises, such as the trafficking of women and girls, forced prostitution, sweatshop labor, female genital mutilation and the severe human rights abuses against women and girls are beginning to receive international attention thanks to concerted efforts of feminist activists.

THE STATUS OF PEOPLE WITH DISABILITIES: EVOLVING STRUGGLES

The number of people with disabilities is rising. In the year 2000, approximately 13 percent of the world's population, or 846 million people, will be people with disabilities. And of those, four-fifths will reside in developing countries (Davis 1998). The experience of disability, although certainly not amorphous, has its own range of cultural meanings depending on the particular culture and disability. Factors such as the gender, race and economic status of the person with a disability influence attitudes, as well. The universal truth remains, however, that like women, people with disabilities as a class suffer from poor social status, disproportionate poverty and deprivation by virtue of the disability. In the U.S.A., a country with civil rights protections against discrimination in employment, only 28 percent of people with disabilities of working age who want to work were employed in 1995 (National Council of Disability 1996: 59). For women with disabilities, the statistics are worse (ibid.).

When women pioneers of the Disability Rights and Independent Living Movement organize, they are historically, politically and philosophically linked to the U.S. Civil Rights Movement that emerged in the 1960s and 1970s. The transformation of people with disabilities *from* *caste to class* and of disability policy *from good will to civil rights* did not evolve suddenly but after a long-fought strategic effort by millions of participants. The new movement demanded independence and community living, not institutionalization; full inclusion, not segregation; disability rights, not special favors. As the free speech, black power, gay and lesbian rights, anti-war, feminist and other movements arose to examine the oppressive forces imbedded in American society, such as racism and sexism, people with disabilities, too, questioned the biological definition of disability. Just as feminists identified institutionalized sexism as a societal evil that devalued women because of their socially defined gender roles, disabled people exposed many of the myths associated with living with disability. Activists knew from experience that public policy reflecting myths, stereotypes, fears and ignorance about disability rather than actual physical or mental limitations posed the deepest oppression defining their struggles. In addition, lack of access to schools, town halls, polling places and recreational facilities, for example, kept disabled people virtually segregated as second class citizens. This further exacerbated public misperceptions. In turn, disabled activists began to speak out, rally and protest against limiting policies and oppressive attitudes.

Due in large part to this activism, over the past 30 years various political, legal and social factors have combined to shift the disability paradigm. The prevailing view of disability in the 1960s was one of a charity or medical model, in which dependent and ill *patients*, disconnected from the rest of society, should be individually *helped* by means of patronizing policies, including legally sanctioned segregation. The alternative view regarded disability from a civil rights perspective in which individuals with disabilities recognized that it was the institutional barriers to full participation in society that needed a cure, rather than their physical or mental limitations. An example of this analysis integrally connected to the Independent Living Movement is that it is not a wheelchair user's inability to climb stairs that is a problem but the lack of alternative access, such as ramps. The charity model social expectation is that such a person could not participate (in school, work, social life) because she is unable, passive, pitiful, sick, dependent, weak, etc. Under the civil rights model, by contrast, it is clear that she is instead systematically excluded by architectural and attitudinal barriers, her disability notwithstanding. As with similar oppressed groups that found power in group identity or rallied around their minority status, the social formation of the Disability Rights Movement was both a result of and a major impetus behind legislative and judicial change. Activists lobbied policy-makers to address such basic issues as architectural access, legal segregation in schooling and institutionalization of people with disabilities. The struggle for civil and human rights protections, and the shift from the medical or rehabilitation model to an independent living or civil rights model, challenges all the stereotypical notions people have had about disability for centuries.[1] The myth that *disabled* means *unable* cannot be sustained in this emerging conception of disability human rights (Kern 1997).

The case of Uganda illustrates what is possible. In spite and because of decades of repression under authoritarian regimes, the disability movement of Uganda achieved some significant victories in the new Ugandan Constitution:

> The right of persons with disabilities to respect and human dignity shall be recognized by the state and society and the state shall take appropriate measures to ensure that persons with disabilities realize their full mental and physical potential. (Disability Action and Awareness Newsletter 1995: 9)

The Constitution requires that five members of Parliament represent people with disabilities, including at least one disabled women's representative. In addition, the deaf community of Uganda lobbied successfully for inclusion of Sign Language as an official language.

THE STATUS OF WOMEN WITH DISABILITIES: AT THE BOTTOM OF THE HEAP

Where femaleness and disability intersect, cultural values, expectations and attitudes come close to being universally negative. As many others have written, by virtue of our status as women and people with disabilities, we are *doubly disadvantaged* and face the *dual discrimination* of both sexism and disability bias. Women with disabilities and those isolated in rural regions, the vast majority in developing countries, face even more barriers to inclusion in their societies. Low cultural expectations and stigma remain the norm, resulting in our own self-devaluation as disabled women. Negative societal stereotypes of disabled women include the notion that we are passive, weak, asexual, dependent, unable to have spouses, children, jobs or rights. These myths reinforce and contribute to our low social status as, truly, the poorest of the poor. Women with disabilities are more likely than other women or than disabled men to be violated, institutionalized, sterilized, isolated, denied access to our own children. It is by far the exception that we are encouraged to fulfill our human potential.

As a Ugandan woman writes of her disability experience:

> The disadvantages of disabled women begin in childhood, because parents look on their disabled daughters as a curse from God. As in any other African society, all girls have very little chance to go to school. They are to stay at home, help their mothers in household activities, get married and bring cows and wealth to the family. The situation worsens when you are disabled. First of all, there is no hope of you bringing cows and other material wealth to the family since it is widely believed that you will not marry because you are disabled. As if that was not enough, parents say they won't waste their money sending disabled children to school when they don't have enough resources to send their able-bodied children. (Kinene 1995: 7)

The prevalent attitude that women and girls with disabilities cannot help support the family or successfully marry allows a family to neglect its daughters' education. This cultural devaluation of females with disabilities remains commonplace in societies worldwide.

WOMEN AND GIRLS WITH DISABILITIES IN REHABILITATION: BARRIERS TO ACCESS[2]

What is rehabilitation for women with disabilities in developing countries? Rehabilitation provides access to the tools, education, training and peer support needed for full integration into the social and political life of their communities. Identified barriers to disabled women's participation in all aspects of society, including rehabilitation services, include (Boylan 1991: 28):

Societal Barriers

- poverty
- illiteracy
- lack of education, training and skills
- rural women's isolation from services
- inaccessible buildings and transportation to services
- parental overprotection
- cultural conflicts between rehabilitation and local customs
- low self-esteem
- burdens of single parenting

In addition, women with disabilities
- are more likely to be destitute, under-nourished, unemployed; without family support, illiterate and without vocational training;
- have less access to rehabilitation and appropriate services.

Male Privilege
The common practice in many cultures of devaluing women and girls in favor of males presents grave disparities:
- disabled girls have higher mortality rates than disabled males. Males are often given preference when food is scarce (Abu-Habib 1997: 73). This is true of assistive aids and devices such as wheelchairs, as well. In Uganda, at least 100,000 people need wheelchairs, due primarily to polio. While more than half are women, only 1 percent of women have them.
- only 1–2 percent of disabled children in developing countries receive any primary education; disabled boys are more likely than girls to attend school (IDEAS 1995).

ACCESS TO REHABILITATION

The opportunities for rehabilitation in developing countries are bleak for everyone when we consider that 80 percent of people with disabilities worldwide reside in developing countries where only 10 percent of all rehabilitation services occur (Boylan 1991: 28). Given this stark reality and the facts that only 2 percent of disabled people in developing countries receive any rehabilitation whatsoever (UNESCO 1995: 13) and that "women and girls with disabilities receive inadequate–if any–rehabilitation services because the very limited available resources are directed toward adult men" (Lewis/Sygall 1997: XII) we must acknowledge that girls and women with disabilities are vastly underserved and examine the root causes. The preference for rehabilitating war veterans before others poses difficulties for women, girls and other civilians in need of services, as well. In Palestine, the division was clear:

> the high profile given to disabled people as a result of the Intifada had inevitably meant a focus on the physical injuries of young men, (t)his focus deflected the disability debate away not only from women, who also suffered during the Intifada, but also against those with congenital or non-physical impairments. (Atshan 1997: 55)

According to women with disabilities living in developing countries, if they survive their injuries or disabilities, some of the factors restricting disabled women and girls' access to services include negative attitudes in the form of traditional concepts and prejudices. In rural areas, for instance, women traditionally stay at home and are responsible for caring for family and household.[3] In societies where women are regarded as an investment, a disabled woman is often (considered) worthless and therefore educating her is a waste (ibid.). Rehabilitation programs appear to have been designed to suit disabled men's aspiration to recover their masculinity and sexuality, while the needs and aspirations of disabled women are often ignored (Abu-Habib 1993: 4). African cultures and religions, as practiced today, oppress women. Women do most of the household chores while men relax; they work twice as hard as men (Tandon 1995: 19). In Zambia one woman writes:

> Because women with disabilities are multiply handicapped in that they are female, illiterate, disabled and live in rural areas, they do not benefit from the available rehabilitation services as they legally could. (Boylan 1991: 28)

Most rehabilitation services are male-oriented. Education is an uphill struggle for disabled women and society seems to take for granted that disabled men should be employed but that disabled women are to remain dependent throughout their lives (ibid.).

Women with disabilities have not, until very recently, been integrated into mainstream community development initiatives. Even the International Labor Organization, which strives to insure 50 percent female participation in its technical cooperative projects, falls drastically short. Of 1,900 disabled persons trained or receiving vocational support in ILO sponsored projects, only 21 percent were women (cf. note 2). There are notable exceptions which I describe later, but the general rule remains that without specific outreach and attention to the needs of disabled women, women's programs and disability projects will not be inclusive of women with disabilities. The several women with disabilities I am working with in East Africa demonstrate their creativity and entrepreneurial skills daily as they support their families alone, make and market crafts, navigate difficult physical environments and, in two cases, run for regional governmental posts. What they need is access to start-up capital and technical support to fulfill their business potential. Their creativity and skills have been honed by virtue of their ability to survive, but they continue to struggle with the burden of poverty.

If we recognize that women with disabilities experience less access to and more discrimination in rehabilitation projects than men (Boylan 1991: 25), the goal should be clear: *to work together to devise and implement strategies for including women with disabilities more fully in rehabilitation and development projects to learn income-generating skills.*

THE WHIRLWIND NETWORK: ATTEMPTS AT INCLUSION FOR WOMEN MEET STRONG RESISTANCE.

The story of the Whirlwind Network demonstrates that even a *rehabilitation project* by and for people with disabilities, in which women with disabilities have been active and instrumental, poses problems for women's ongoing participation. In most of the developing world, even today, the best hope of obtaining a wheelchair rests with Western charity: and this really means a non-repairable *hand-me-down* wheelchair, inappropriate for essentially everything but the hallways of a hospital, with someone else pushing. This is not exactly a prescription for independence. Without any mobility, the disabled people of developing countries remain hidden away, in isolated villages, with no hope of meeting others with disabilities, often dying from preventable pressure sores and other infections.

In 1980, with start up funds from USAID and a collaborative training with Ralf Hotchkiss, several Nicaraguan teenagers started building an early version of the Torbellino, or Whirlwind, for disabled people in their communities. This was the first shop in the Whirlwind Network; the Network has expanded in the last 18 years to include 35 shops in 25 countries, with each shop building a version of the Whirlwind. *As some shops succeeded and others failed, the Nicaraguans realized that shops run by the users of the chairs themselves were most likely to stay in business.* Shops run by wheelchair riders make the most durable chairs, and have a history of coming up with more improvements – new inventions – than the shops run by wheelchair non-users. Over time the Nicaraguans developed a philosophy that guides the development of the Whirlwind Network today: *people with disabilities – especially the wheelchair riders themselves – must be leaders at every level, from design to sales, in the making of the Whirlwind.* Disability leadership is essential, both to creating the quality of wheelchairs that we need and to the struggle for the most basic human rights of those of us with disabilities. It is the riders navigating our lives on wheels whose input is vital. But where was women's participation?

WHIRLWIND WOMEN

Whirlwind Women was founded in 1994, to fill the gap and provide training and support for women interested in creating their own mobility options. Over an eighteen-year period women have made major design and technological contributions to the ever-evolving Whirlwind wheelchair, such as the jump seat or second seat used to assist in transferring, permit access to the ground, transport children or firewood and also serve as a seat for a pit latrine, if no outhouse seat is accessible. Other contributions by women include the triangular side frame and stabilizing chain that keeps the wheelchair together when folded. Women's input into the design, however, did not translate into support for their involvement in the shops where men dominated in every way. The sad truth is, without sufficient support, even the most skilled women technicians rarely have remained long in male dominated wheelchair shops. Historically, those who stay have been isolated and assigned to the traditional *women's* work of sewing the chair fabric. In the Philippines, of the twenty shop workers only one was a woman, and she sewed the fabric. The reasons have many cultural aspects such as endemic machismo and sexism, low expectations, condescension and patronizing attitudes. Even the notion that a woman could weld, drill, saw and build a wheelchair is revolutionary in most communities worldwide. Providing the opportunity is even more difficult. In Palestine, cultural barriers prohibit women from working in the shop and receiving training. In other regions, women allowed in shops are still considered less able, yet even their presence threatens men. A classic story is of men *assisting* women with a task, and then walking away with the necessary tool she was using. Other problems include men being possessive of heavier, more dangerous jobs. This tendency to overprotect is compounded when the woman technician has a disability. When I was building my first Whirlwind, I worked with a very nice fellow who felt he should do everything for me including most of the welding, instead of allowing me to learn each task with the rest of the class. I happen to like welding, and insisted. I got my chance, but I could easily have been dissuaded from learning. And there are classic harassment issues that women everywhere face. When one young woman was teaching in Mexico, she had to deal with men not listening to her, flirting with her and touching her inappropriately. Only because an older Mexican woman supported her did the men back off and take her seriously.

There are positive examples of women receiving sufficient support to fully participate, thereby strengthening the whole shop or training. Just as in the disability rights or any traditionally male dominated movement, the key is for enough women to participate and to support each other that a critical mass forms, serving to strengthen the women's confidence and resolve.

- In a Cambodian shop, a blind woman leads a team of five blind workers who earn their living spoking all the wheels. By now, her team has spoked more than 8,000 wheels. Several other women work in the shop on a variety of tasks, lending crucial moral support.
- In Nicaragua, a few isolated women started out as mechanics. They were subsequently pushed out of the shops due to hostile work environments caused by the men. Now the women are forming coalitions to remedy past discrimination. Currently, three groups led by disabled women plan to repair wheelchairs after they secure tools and training.
- In January 1997 in Limuru, Kenya, Whirlwind Women conducted a week-long intensive training in basic tool use for women and worked with three women from Disabled Women's Network and Resource Organization DWNRO of Uganda and three Kenyan women. The women's intensive training preceded a three-week course in Whirlwind wheelchair design and production attended by twelve male mechanics. The pre-training for women fostered a sense of community necessary to ward off feelings of inability and insecurity in the shop. Whirlwind Women and the DWNRO representatives, independent, strong single mothers supporting their families, built two Whirlwinds and left the training determined to work toward opening a women-run Whirlwind production shop in Uganda where no folding chairs are currently made. The project will begin this summer.
- In Kenya, Peninah Mutinda has started a woman run Whirlwind building shop with a grant from the Global Fund for Women, to compete with other local shops.

COMMUNITY BASED REHABILITATION

The major shifts in the thinking about rehabilitation that are manifest in Community Based Rehabilitation or CBR are emerging as a potential way to combat some barriers to rehabilitation services for all disabled people through promoting social integration, equal opportunity and community involvement of people with disabilities (Boylan 1991: 25; Tandon 1995). In theory, context-oriented programs and projects sensitive to individual, family and community needs should begin to bridge the huge gap between disabled women and their access to necessary medical, vocational and social services. To the extent that CBR remains participatory, community driven and controlled, and promotes skills, confidence and empowerment for, not control over, people with disabilities, the community-centered philosophy of CBR should bode well for women's increasing participation in training activities.

WOMEN IN DEVELOPMENT

Similarly, the emerging consciousness of women's pivotal role in development broadens the spectrum of opportunities for all women in developing countries. The international development community led by entities such the Grameen Bank, a micro-lender that began in Bangladesh, has acknowledged that investing in women makes good business sense. "Grameen found that by lending to women, profits were used to improve the family's quality of life, and led to a rise in women's status."[4] Women, especially working in groups, have demonstrated their skills when given the opportunity to decrease their economic marginality. As such, they are credible risks for loans. Now, disabled women are seeking ways to tap into this and other development resources and mainstream women's projects as a means to support their families and increase autonomy.[5] (Lewis/Sygall 1997: XI) While both CBR for people with disabilities, evolving development models and vocational training for poor women offer greater possibilities for women with disabilities, a risk is that women with disabilities may fall between the cracks of these progressive trends. Disabled women indicate that they may not yet be adequately benefiting from these services. A 1990 survey determined that of 55 successful skills training projects for women in Africa, none involved women with disabilities (Boylan 1991: 28). Recommendations from the survey state:

> in planning income-generating activities, experts, after having assessed local and/or national markets, should take care that disabled women are not only introduced to activities traditionally occupied by women. Often, there are viable alternatives to knitting and weaving.

And disabled women at a conference in Entebbe agree that "women should not limit themselves to *traditional* types of activities, such as secretarial work. They should look into new opportunities such as electronics, radio repairs, computers, etc." (Tandon 1995: 19).

Some positive examples of projects designed to be inclusive of disabled women's needs are:

- Improved Livelihood for Disabled Women in Botswana, Zambia, Zimbabwe, Lesotho and Swaziland, an ILO project funded by the German government, works to change attitudes about women with disabilities. It also

  > promotes participation of women with disabilities in mainstream projects, to ensure access to productive employment, education, training and community activities. (Lewis/Sygall 1997: 50)

  Examples of income-producing activities women with disabilities were trained to do were bookbinding, cardboard furniture making, leatherwork, cement block making, secretarial and photocopying services. In addition, working with both women's groups and national organizations of disabled people, disabled women were trained to run a maize-grinding mill (ibid.: 52).
- In Tanzania, CHAWATA, the Tanzania Association of the Disabled has a Women's Development program, formed in 1992. They support women's participation in CBR, vocational rehabilitation, production of mobility aids and revolving loan programs. Women's projects include: tailoring, groceries, weaving, pottery, gardening and sale of commodities in markets (ibid.: 38).
- The Ugandan Disabled Women's Whirlwind Wheelchair Project will bring together disabled and non-disabled women in a collaborative pilot project, teaching wheelchair building skills as a means of generating income and of producing wheelchairs for Ugandans with disabilities. In each case, women work together, with support, to earn income while filling a community need.

Such models of rehabilitation that recognize the considerable skill that women with disabilities bring to their lives every day will shift the focus from *what needs to be fixed?* to *given the abilities present, what are ways to optimize independence, health and income generating skills and opportunities?* The key, I believe, is to include women with disabilities in the problem solving. Ask us what we need and how we propose to get it and what needs to be done to help. Support us in strengthening our movements from the ground up. Acknowledge that we have expertise from our life experiences. Listen to our suggestions; support us and learn from our successful projects. Work with us as resources and allies as part of a team, not as outsider experts.

ANTIDOTE TO EXCLUSION AND OPPRESSION: THE EMERGENCE OF AN INTERNATIONAL MOVEMENT OF ACTIVIST WOMEN WITH DISABILITIES

Many of us have been brought up to have limited expectations of ourselves and our future quality of life; to believe that we are not entitled to a voice, a place, a vote. Yet increasing numbers of disabled women are finding value within ourselves and pride in our collective identity.[6] Despite the strong cultural links between women and people with disabilities worldwide, neither the Disability Human Rights Movement nor the Women's Human Rights Movement has historically sought to include issues of women with disabilities in their political agendas (Blackwell-Stratton 1988: 307; O'Toole 1997: 127; Lakkis 1997). Fortunately, a growing international movement of activist women with disabilities recognizes the value of all girls and women with disabilities as a vital part of the human family. We are speaking out about negative cultural values and lack of rights, services and opportunities, forced sterilization, female genital mutilation and eugenics, among other things. We know our skills and abilities have been consistently overlooked, that our existence has been devalued and our quality of life denied. And we are working to end these forms of discrimination by educating our families, communities, health care and rehabilitation providers in ways that fully integrate women with disabilities into societies.

Roseangela Berman Bieler, a Brazilian activist leader, reminds us:

> It is hard to ponder over disabled women's grievances separately from the fundamental social problems (such) as prejudice, ignorance, segregation and lack of civil rights. (Bieler 1997: 97)

Fueled by the desire to address those problems, and unwilling to be unrepresented or spoken for at another international women's conference[7], 200 women with disabilities from over 30 nations gathered outside of Beijing in 1995 for the International Symposium on Issues of Women with Disabilities sponsored by the World Institute on Disability and

Mobility International, U.S.A. At the NGO Forum and official U.N. conference we joined together to put our stamp on the international women's movement and assert that we are indeed a necessary force for badly needed social change in communities everywhere. During the NGO Forum, we protested about lack of access to the meetings as we named the problems that we face worldwide: poverty, violence, low self esteem, lack of access to buildings, sign language interpreters, education, training, employment, adequate healthcare, rehabilitation, adaptive equipment and transportation. And we, along with our allies, shared strategies to make those changes in our communities all over the world. Delegates to the official conference representing disabled women successfully lobbied for inclusion of language into the Platform for Action to: "ensure that girls and women of all ages with any form of disability receive supportive services."[8] This recommendation mainstreams the needs of women with disabilities, broadening the potential impact of the 1993 U.N. Standard Rules on the Equalisation of Opportunities of Persons with Disabilities.[9] Both officially acknowledge the need to include disabled women in rehabilitation programs.

We came together again in Bethesda, Maryland last June at the International Leadership Forum for Women with Disabilities, the largest meeting ever dedicated to the international issues of disabled women. Approximately 600 women with disabilities met to keep the momentum going: to network, develop ideas for solving our own problems and celebrate our common links. It is this powerful collective energy that is igniting grassroots activities of disabled women in thousands of communities from Africa to Latin America. Other regional gatherings of women with disabilities in Brazil, Munich, Entebbe and Oregon strengthen our commitment to global and local social change. We know that we as disabled women, working in groups with other disabled women, must define our own futures. We are learning that this takes organization, technical skills and financial support from international development organizations. We are beginning to demonstrate that despite the myths about us, disabled women are serious about inclusion in rehabilitation, social services and equal access to society.

CONCLUSION

A wheelchair or crutch or adaptive device is only part of the rehabilitation process, as are skills training and employment support. These are tools allowing the potential for a fuller life. Women with disabilities are emerging as leaders in this movement, seeking tools and rehabilitation to maximize their potential, more fully participate in their communities, and fight the considerable attitudinal, social and architectural barriers that keep us marginalized.

NOTES

1 Wendell, 1996, see generally chapter two, The Social Construction of Disability. See also A. Asch and M. Fine 1988: 9–12; T. Degener and Y. Koster-Dreese 1995: 15.

2 International Labor Organization Survey in 1990. In: Inside Rehab. No. 6 April 1990.

3 Disabled Women in Countries Cooperating with SHIA, p. 7.

4 Grameen Foundation, U.S.A., brochure.

5 In September 1998, fifteen disabled women leaders from around the world will attend a micro-credit summit with Mobility International U.S.A. to devise ways to participate in the development model of micro-loans in ways that accommodate their needs.

6 Disabled People's International-Europe Women's Committee press release for International Women's Day March 1994-DAA newsletter March 1994.

7 Previous United Nations conferences on women include Mexico City, 1975, Copenhagen, 1980, Nairobi, 1985. Accessibility, disabled participants and disability issues were virtually non-existent at these conferences, even though the Nairobi conference took place during the U.N. International Decade of Disabled Persons.

8 The Beijing Declaration and Platform for Action, The Fourth World Conference on Women, U.N. Doc. A/CONF.177/20 (1995). (Health section). Issues of women and girls with disabilities are included in sections 60(a), 73, 82(a), (g), 83(a), 84(k), 102, 107(c), (o), 110(d), 115, 125(m), 127(d), 180(f), (j), 197(a), 209(k), 226, 232(p), 233(a)(b), 259, 270, 272, 278(d), 280(c).

9 United Nations Documentation A/48/96 (1993).

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"We don't need to be cured first in order to live": Self-help in Oaxaca, Mexico (An Account of an Interview with German Perez Cruz)

Brigitte Holzer

Acceso Libre – *Free Access* – was the name chosen for itself ten years ago by a group of twenty people with various physical disabilities. The name symbolises the group's political goals: Free Access makes entry possible for anyone who wants it. This is the vision with which the organisation's members, people with impaired mobility and wheelchair users, confront the public: a vision of being able to move freely everywhere, and go wherever they want. This meant changing the concrete physical conditions in their environment, and so the members started by calling for ramps to be built in the municipal area and introduced in public buildings. Their work was rewarded: public buildings and each pavement, street or square that was built or repaired got a ramp. A further goal pursued by the association's members is equal access and rights on all levels of social existence, as equal members of society. Today, *Acceso Libre* is a centre which supports the training of young people with disabilities – of whatever kind – and above all, aims at developing awareness: members of society need to learn to be aware of disabled people's abilities, disabled people have to learn to believe in themselves, and their parents have to be prepared to learn with them. Each one of these concerns reveals that the inclusion of people with disabilities in social life is not self-evident.

Living in Dependence

G. Perez Cruz uses his own biography as point of departure to illustrate the complexity of the mechanisms which combine to prevent disabled people from feeling they are full and equal members of society. At the age of six months he got polio, which mainly affected his left leg.

> Soon a period of rehabilitation began, which was very stressful for me. Until I was 18, I was continually travelling to Mexico City with my mother in search of a cure. These journeys had consequences which I only began to assess as an adult. If I had an appointment with a doctor, I never knew beforehand if I would be coming home after one week or four. Sometimes I went to Mexico City and a doctor did nothing more than examine and measure the leg. For this though I would have missed school yet again, and in the end I had lost two years of school. In Mexico City I had a successful operation – at least I can walk now – but it's a hard thing to look back at the end of your youth and come to the conclusion that you haven't developed your own line, you have never structured your own life. Your whole life plan was dependent on outsiders, strangers you didn't know and would never see again. Then, when you're older, your family expects you to give your life some direction, to work or take exams, to go to university. But how could I suddenly take my own life in hand, when it had always been in other people's hands before? They had taken all the decisions in my life, they defined and occupied my spaces, they never gave me what I had needed most from early childhood on: self-confidence and courage. This was a hard thing to take on board. I began to drink.

In a sports club for people with disabilities, G. Perez Cruz met others in the same position. They were unanimous: "Something isn't functioning right in our society. Why should we be cured? Why don't we start much earlier taking opportunities to adapt our lives and their conditions to each other?"

The group of young people began developing their own concept of disability, one which was to become the basis for *Acceso Libre's* work: if society does not know how to fulfill someone's needs because it does not understand them, it labels that person *disabled*. Disability itself is seen as a problem, instead of the external conditions which are not (yet) adapted to the needs of the disabled person. When a ramp is installed, people assume they have solved a problem for the disabled. They don't see that one of many needs has been met. The thinking of the parents reflects this social structure. They bring their child to the doctor with the attitude: "All will be well if our child gets better." The disability however is there and stays there; and the parents' position does nothing to alter the conditions in whose light the disability appears as a problem. The consequences of this are incurable.

The members of *Acceso Libre* perceive a great responsibility for people with disabilities. They say to disabled youngsters and their parents:

> We don't need to be cured in order to live. What we need to do is make our needs known. The parents must accept the disability, not fight against it, and open up the right paths for the child so that it arrives at the point where the disability presents the least hindrance. If the child can develop her or his own way of living, the society will learn to understand it and provide the necessary tools.

In terms of the work done at the centre, this means confronting the indifference and passivity so often found in people with disability, precisely because they are never given any responsibility. Their lives seem to be organised by professionals and parents. They get used to being dependent. Many, for example, come and want to do training, want to learn something (new), but do not see that this requires engagement and effort. This attitude is also reflected in the way Acceso Libre is treated.

> People are always trying to use us as a commercial service provider. They won't see that the centre's very existence revolves around disabled people taking their own lives in hand, and that our work in the centre has to be supported in order to change the social conditions of life with a disability. People have got used to being dependent, and that makes it difficult to create something new.

Acceso Libre lays down clear conditions for those who come to the centre.

> If you want to learn something, you must learn. If you come here because you don't know where else to go, no-one will take any interest in you. The centre isn't a place just to go to and be at, it's a place where you make something of yourself. Your place is out there in society, where you will be confronted with problems which you will solve, slowly but surely.

Parents are integrated into the young people's training. When they visit the centre in search of training for their children, they have to promise their cooperation. They support the concrete organisational work and learning, not standing over their children, but at their sides. *Acceso Libre* does not levy any membership fees.

> Fees create rights and undermine responsibility. No-one must be able to say, Why should I keep working for them, after all, I pay them regularly.

LIVING INDEPENDENTLY

Being able to lead an independent, self-determined life seems to be a common, central goal of self-help movements in many countries. Yet with regard to precisely this goal it becomes clear just how much the meaning of a vision which, on the surface, everyone seems to share, changes according to cultural context. In the conversation with G. Perez Cruz, being able to take responsibility for oneself and others emerges as the most significant feature characterising what is understood by 'an independent life' in Oaxaca. The fact that the life of the individual there is strongly linked to the family plays an important role in this.

> Each member of the family does something that can contribute to the family staying together as a social unit. Particular attention is paid to the mother, because she and the house she lives in are the centre of the small community. A disabled member of the family almost always sees her or himself as a person who cannot contribute to the family's livelihood. This is what creates the acute sense of total dependence. At this point the person with the disability experiences him or herself as unequal and different.

Being able to lead a self-reliant and independent life does not imply managing without the family, but rather becoming a member of the family. Part of this consists in the person with the disability becoming aware of his or her own needs and learning to satisfy them.

> If I need an orthopaedic apparatus in order to walk, I don't wait until someone gives it to me and use an amulet while waiting, instead I know my needs and know how to satisfy them.

G. Perez Cruz gives the example of a young man from a small village whose father brought him to the centre with the words, "I don't know what to do with him any more." The son had injured his spine and was partly paralysed. We worked with him at the centre, and slowly but surely the young fellow began to *grow*. He developed a personality. Three years ago he left the centre, because he had found two jobs. His sister, whom he lived with during his time at the centre, recently lost her husband in an accident, and is now being supported by her brother. He's getting married soon, I don't know how he does it, because actually he never has any time.

THE WORK OF THE CENTRE

The centre *Acceso Libre* is the point of departure for many varied activities related to work for and with people with disabilities. The centre occupies a rented house and has several full-time coordinators for various areas of activity: PR, training, schooling, workshops, rehabilitation, parent participation, training teachers for integrated education, project development, etc. In the centre itself classes and training units aimed at providing a transition to normal schools/places of work are organised. The teaching is based on the principle of *interactive learning* (the participants teach each other), which means less spending on resources (teachers). In November 1998 the centre coordinated the first Forum of Latin American Women with Disabilities, attended by 40 women from eight different countries.

An increasingly important area of the centre's work are the *Centros de Recursos*, which workers at the centre hope to establish and coordinate in rural areas. The problem for people with disabilities in rural areas is different from in the city. On the one hand, the communities protect *their thickies* (*El Loquiito*), *their gammy leg* (*El Cojito*). On the other they often isolate them as well. They are frequently not given any functions and so cannot relate to others, and have no personal relationships.

> Once people are in the position to fill a place, doors are opened to them. The most important resource that our work in the centre mobilises in the people affected is self-confidence. They get to know their needs and how to meet them. Back in their villages this is in fact what is so important: conveying what they know about their special needs.

MONEY SHOULD NOT BE THE PROBLEM

Acceso Libre wants to work with universities to facilitate studies of material, ecological and social basics. The results would then be used as guidelines to establish what kind of production centre or other amalgamation would be meaningful for securing livelihoods.

> When we want to start any kind of activity, we always come up against the problem that people think of the money which appears to be necessary and is mostly not available. There are so many resources, particularly in rural areas, which must be intelligently mobilised. The activities are not first and foremost a question of money. We don't

> need a computer or a typewriter for a rural centre. We need the support of people. Young people often have time to spare; one could get them interested in the interactive learning, for example. Recently someone donated us a site for a rehabilitation centre 20 metres from a beautiful lagoon. It would be possible to negotiate with the communities. Give us this or that, and we will keep the park in the centre in order.

The self-help centre in Oaxaca City itself provides a secure and more or less well-paid job for many people with disabilities. At present though, the workers are finding out the hard way how long and how well it can keep going without regular financial support. From March to September they have to go without the Kellogg Foundation's donation.

THE PAN-AFRICAN MOVEMENT OF PEOPLE WITH DISABILITIES

Joshua T. Malinga

HISTORY OF THE MOVEMENT

For two thousand years disabled people were publicly viewed and presented as sick, stupid, semi-idiotic, asexual and as people who cannot do anything for themselves. They needed other people to do things for them and to them. They were the *deserving poor* and were given licences to be beggars and some were put into institutions in order for them to be rehabilitated, rehabilitated and rehabilitated and then be *farmed* back into the world of the able-bodied where there are not facilities for disabled people. Disabled people remained excluded from all systems of community services such as transport, education, employment, sports and recreation, and others. Disability issues were not part of economic, political, cultural or social systems.

PURPOSE, ROLE AND FUNCTIONS OF ORGANISATIONS OF DISABLED PEOPLE

The development and growth of organisations of the disabled over the last twenty years has seen disabled people setting the terms of their participation in their communities and society. The paradigm shift from the medical to social approach has dramatically changed the attitudes towards disabled people and also changed the attitudes of disabled people towards themselves. They are no longer seen as objects of charity and pity and problems for society.

The declarations of the 1981 International Year of Disabled Persons and Decade of Disabled Persons (1983-1992) made a great impact by bringing disabled people together from all over the world to share experiences and a great deal of latent energy was released. Disabled people started organising und uniting to create united voices at all levels.

The world has never been the same since. Disability is now on the social and political agenda and disabled people are out in the streets demonstrating and demanding full and equal participation in society and access to the general systems of society and to what others enjoy as a matter of course and as their right.

This is what the movement has achieved internationally in the short period of twenty years. It has created grassroots democratic national organisations of disabled people and voices of disabled people locally, nationally, regionally, continentally and internationally.

SITUATION OF DISABLED PEOPLE IN AFRICA AND THE ROLE OF THE PAN-AFRICA FEDERATION OF THE DISABLED (PAFOD)

While disabled people everywhere suffer similar discriminatory practices and negative attitudes, disability in Africa is a life and death issue, a question of survival. Disabled people in Africa are fighting for basic human rights and have no access to basic human necessities and appliances. Most governments do not include the needs of disabled people in their national socio-economic planning and programmes. Since government funding is often scarce, most services for disabled Africans have historically been provided by charitable organisations, often funded by donors from industrialised countries. For example, special schools and hospitals catering for the needs of people with particular impairments have been a feature of African society for many years. But many of these organisations fail to involve disabled people in decision-making about the services they want.

Spurred on by the achievements of other groups, such as the women's, workers' and black civil rights movements, disabled Africans have begun to discuss amongst themselves how they wish to be represented and how they can take control of their lives. Increasingly, disabled Africans realise that they face common barriers in education, employment, access to services and information – and that they are in the best position to know the solution to the problems they face. In the last two decades, organisations *of* disabled people have sprung up throughout the continent at all levels. They provide forums for discussion and action, representing the opinions and concerns of disabled people in ways which organisations *for* disabled people never can. By linking together nationally and internationally, a new civil rights movement in Africa has been born.

PAFOD was formed in 1994 in Zambia, based on the philosophy that disabled Africans are in the best position to know the solutions to the problems they face. The main objective of PAFOD is to develop and strengthen national organisations in Africa and provide an umbrella forum for disabled Africans and their governments to discuss issues of full participation by disabled people and violation of the rights of disabled persons in Africa. PAFOD also represents disabled people and seeks to influence policy decisions in favour of disabled people at continental level (OAU) and within regional, economic and political entities such as the Southern African Development Community (SADC) and the Economic Community of West African States (ECOWAS).

PAFOD is a co-ordinating committee comprising the five sub-regional federations of grassroots umbrella organisations of disabled people in Africa:

- Southern Africa Federation of the Disabled (SAFOD)
- North Africa Federation of the Disabled (NAFOD)
- East Africa Federation of the Disabled (EAFOD)
- West Africa Federation of the Disabled (WAFOD)
- Central Africa Federation of the Disabled (CAFOD)

ACHIEVEMENTS

There is much to celebrate, thanks to the efforts of African organisations of disabled people. In recent years they have:

- Influenced policy makers to pass legislation and support programmes for disabled people's rights and integration.
- Helped to raise the status of disabled people, highlighting the inequality which disabled people face.
- Shown appropriate ways in which equality of opportunity can be achieved.
- Been actively involved in the formation of constitutions.
- Helped to elect disabled Members of Parliament.

  PAFOD is also actively promoting UN human rights instruments including the World Programme of Action concerning Disabled Persons (WPACDP) and Standard Rules on Equalisation of Opportunities for Disabled People as a basis for policy formulation and legislation.

SELF-DETERMINED LIVING IN GERMANY

Ottmar Miles-Paul

THE STARTING POINT

In all the countries of the world, and in all social strata, disabled people have the experience of being excluded and disadvantaged. On the one hand, they reap a harvest of many good words and enormous efforts are made to assist them. On the other hand, they experience on a daily basis how decisions affecting them are made without their input and how measures are conceptualized and carried out against their interests.

- Facilities and projects for disabled people are almost always planned and run by non-disabled *experts* without those affected having any serious influence on the basic conditions. In the hiring of employees in institutions, for example, the residents are seldom consulted in any way, although they are the ones who sometimes have to live with the employee for a long time.
- Since societal efforts to promote them are lacking, disabled people are underrepresented in political parties and legislative bodies. As a result, parliamentary debates are usually conducted and decisions made without any input from people who might be affected. Many polling stations, for example, are inaccessible to people in wheelchairs.
- Even in most so-called organizations for the disabled, it is parents, care-givers or well meaning non-disabled people who run things. This frequently results in the lack of an atmosphere in which disabled people can grow and gain influence, not to mention the lack of an atmosphere in which their interests are represented appropriately. Is it surprising, then, that disabled people are so infrequently quoted in the media?
- The picture in the minds of many non-disabled people with whom disabled individuals have to deal on a daily basis, and by which they are seriously affected, tends to be that of needy child-like creatures. Disabled people are mainly seen as suffering, and needing to be cared

for, rather than as fellow citizens with the same rights who are regarded as equals.

Hidden under the cloak of charity and *We only want what's best for you*, a motto which makes any dialog based on equality impossible, we continue to see today a high degree of segregation and a great deal of discrimination in the work being done for disabled people. This is accompanied by ignorance, egotism and helplessness on the part of those who have only the best intentions in regard to the disabled. In accordance with the saying *The way to Hell is paved with good intentions*, disabled people today are still being exposed to the most extreme human rights violations and discriminatory practices without any large-scale public opposition being organized to fight against it. Non-disabled persons who take the side of the disabled often experience repression in the facility where they work or are not hired in the first place.

Above all, Western societies continue to waste enormous amounts of funds and resources on ineffective, and to a certain extent, counterproductive, services *for* disabled people – a waste that has resulted in the non-participation of precisely those with whom it has to do. According to an assessment of the former advisor on disabilities to the American presidents George Bush and Bill Clinton, Justin Dart, who is also a wheelchair user, the exclusion of and discrimination against disabled people costs American society over $ 200,000,000 annually. The consequence of this realization was already obvious in the 1970s and 1980s. That is, that disabled people – like almost all other minorities – have to get involved and fight for their own rights. The illusion that others could do it better than themselves was destroyed as early as the big congresses of rehabilitation experts at the beginning of the 1980s. At the conferences it became apparent that, despite their active commitment and expertise in this area, they were only allowed to play a peripheral role and their involvement in the proceedings was secondary to the career advancement activities of the non-disabled participants. Today, under the umbrella of the Disabled People's International, disabled people have founded organizations to advance their cause in more than 110 countries around the world. These organizations are run by disabled people and promote the self advocacy and self determination of the members. These organizations have promoted major initiatives that have resulted in advancements like equal rights laws and the UN Standard Rules of Equal Opportunity for Disabled People which have set new standards for policies affecting disabled people.

BASIC PRINCIPLES OF A SELF DETERMINED LIFE

The concept of self determination for the disabled means not just that people with disabilities must be allowed the possibility of exercising control over their own lives, but also means enabling them to become active on their own behalf, to fulfill social roles and to take the responsibility that arises from such activity. To make sure that this happens, the movement for disabled people has formulated six basic principles. These principles represent the goals that the movement is working towards in addition to rewriting the political program of this new movement.

1. With the demand for comprehensive and legally binding equality and anti-discrimination legislation in regard to disabled people, a decrease in discrimination against the disabled will be secured and equal opportunity in crucial areas will be mandated. These crucial areas include housing, education, employment, access to public buildings and public transportation and to the use of telecommunication facilities.
2. Through striving for the *demedicalization* of disability, the often limitless dominance of the medical profession in this area will be reduced and the taking of responsibility and the access to power of disabled people, to make decisions affecting their lives, will be promoted. Through the development of forms of independent organization of care (disabled people as employers of their care givers) people with disabilities are demanding a long overdue power transition; a transition, that is, from being passive patients to being active consumers and managers of their personal assistance. This leads to the subject of who is able to decide who gives help, when and what help, and how and where it is given. Additionally, through this process of the demedicalization of disability, the often artificial separation of single groups of disabled people, by sorting the disabled into special grades based on severity of disability, will be abolished. This will make solidarity and co-operation that bridges specific disabilities possible among disabled people. Being disabled is not just a question of type and severity of disability but also of the social and power relations that determine their lives.
3. The principle of non-segregation and the greatest possible integration into the life of the community rejects any involuntary separation and institutionalization of the disabled and reinforces the demand for community oriented supportive services so that people with disabilities will be allowed a real range of choices with the greatest possible

degree of self determination. In this way, a life with equal rights, lived in freely chosen surroundings, is made possible for disabled people.

4. With the demand for the greatest possible control of disabled people over their own organizations, the movement for self-determined living for the disabled calls for something which in other social movements, for example in the women's movement, has long been a matter of consensus and which is also becoming standard in the area of disability. That is, that those directly affected have control over the leadership of their organizations, represent the organizations in public and themselves determine the political goals and policies of these organizations.
5. It is necessary to insure in the future that the work with the disabled, which is now part of a welfare industry worth billions of German marks, is really focused on the interests of those whom it is primarily intended to serve – namely on those of the disabled and not on the interests and constraints of the professional organizations. To accomplish this, the greatest possible degree of control over services for the disabled by the disabled themselves is demanded.
6. With the principle of peer counseling, and peer support as the key to the empowerment of disabled people, the members of the movement for self-determined living thus commit themselves to mutual support, advice and to promoting each other. This commitment will enable more and more disabled people to travel the rocky road to self-determination and, in addition, make it possible for them to take on the responsibility in our society that goes along with it. Correspondingly, the future priority of the promotion of advisory services is called for so that the principle of peer counseling – the advising of disabled people by disabled people – can be fulfilled. This will allow the empowerment of disabled people to proceed on a large scale basis.

Perspectives and Challenges

Kalle Konkolla, the world president of Disabled Peoples' International, who is from Finland, usually asserts the following when there is more complaining going on about problems than efforts being made to solve them: "We don't have problems. We just have challenges!" This statement is true for the movement for the disabled and, thus, for all professional work with disabled people. While the disabled movement has, on the one hand, set up an extensive network of facilities, especially in the

Western countries, these facilities, on the other hand, have contributed significantly to the segregation and dependency of disabled people, due to institutional structures and constraints. As a result, we must now, more than ever before, accomplish a radical change to the empowerment of people with disabilities and to their open participation in society. This means an enormous transformation in their role for many disabled people, one that must lead them beyond the care that formerly prevented them from becoming experimenters and active agents in their own affairs. This will not happen from one day to the next, requires positive role models for those affected by disability and, above all, a deliberate effort to promote disabled people, without putting them in a subordinate role. The good, but also the difficult, thing about this process is that it must mainly be accomplished by disabled people themselves since emancipation cannot be ordained or dictated.

The society and its institutions are presented with the following challenges if people with disabilities are to be supported in their emancipation.

- The facilities devoted to professional work with the disabled, and those people employed in this field, must develop and carry out plans that support the organizations for disabled people, which chronically suffer from lack of funding and personnel, and do so without relegating these organizations to a subordinate status. On the one hand, this is a big challenge for both sides. On the other hand, it also offers a variety of unsuspected possibilities for the disabled individuals who are supposed to be what it is ultimately all about. Because the knowledge in this area that has been gained over the last twenty years clearly indicates that the best education or training, without an accompanying high level of self confidence on the part of those affected, often leads nowhere.
- The involvement of disabled people in the political decision-making process must be deliberately promoted. The central preconditions for this are the making accessible of all public events to people characterized by the widest range of disabilities, the motivating of disabled people to take part in political processes and naturally also the readiness of the political parties to share power and to choose disabled persons as candidates for elective offices.
- Last but not least, our attitude above all will be crucial in determining how far we develop from being a *well meaning* society to one that actually does well in respect to the disabled. To find out if we, with our ideas and plans, are on the right path, it will always be indispensable to sit down with those primarily affected, take their opinions

> seriously into consideration and support the implementation of these. It is irrelevant how quickly or slowly we move in this direction; the time when the disabled accept, without opposition, practices that are against their interests, is coming to an end.

The slogan *Nothing About Us Without Us* is not just one proposition among many but, more and more, is becoming the standard program statement of a civil rights movement whose members are fighting for their rights. The general public must fight with them so that *in reality, nothing which affects disabled people takes place without their active participation.*

TOWARDS NEW APPROACHES IN THE STUDY OF DISABILITY IN AN INTERCULTURAL FRAMEWORK

GENERAL ISSUES IN RESEARCH ON LOCAL CONCEPTS AND BELIEFS ABOUT DISABILITY

Nora Ellen Groce

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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DEVELOPING LOCAL CONCEPTS OF DISABILITY: CULTURAL THEORY AND RESEARCH PROSPECTS

Patrick J. Devlieger

INTRODUCTION

The anthropology of disability involves an understanding of disability as a social and cultural phenomenon. Within such a perspective, disability is created by virtue of the presence of different human bodies and their societies. Disability is not an immutable, well-defined phenomenon but one that can be understood as a universal local process. In other words, all societies must address bodily difference in their local cultural contexts. Locally produced knowledge of bodily difference involves both discourse and practice. Local knowledge of disability has been dismissed and repressed during colonial and post-colonial times as backward and irrelevant. Colonial initiatives geared to disability have largely taken Western concepts to direct initiatives of disability. Professional and scientific discourses have maintained this trend during postcolonial times. Most recently, disability advocates in the disability rights movement, speaking both in global and local contexts, have stressed that locally produced knowledge of disability is oppressive (Charlton 1998). I contend in this article that foreign discourses of disability may be culturally alienating and ultimately of little impact. Instead, I argue that research on local knowledge of disability and its cultural critique may offer an alternative towards development that is culturally rooted. In this article, I provide an agenda for research on local concepts of disability that is situated in an alternative cultural theory of disability. I define disability as a universal interstitial social status, i.e., a status that places itself between recognized categories and statuses and that is neither marginal nor elevated. This interstitial social status is neither good nor bad but always a challenge to a pre-organized world and mutually challenging for both the disabled individual and her social and cultural environment. An interstitial social status challenges culturally normative expression and communication and demands alternatives from which disability, as cultural and social phenomenon, is identified and developed as a discourse. First, I situate disability in a contemporary context and show the need for research that documents disability as a local category. Then, I briefly take up the cultural theory of disability as an interstitial category and provide an agenda for research into local conceptualization of disability.

LOCAL AND GLOBAL CHALLENGES TO DISABILITY DISCOURSE

The concept of disability has been informed by cultures and by the history of Western nations. The concept is not fixed but highly ambiguous because what constitutes a disability is subject to personal, social and societal recognition. It happens that in Western societies the concept of disability as one that covers a number of disparate impairments is constantly being revised and therefore subject to new layers of meaning. The relationship between a society and its disabled members is one that is constantly emerging. This means that disability is historically variable and always a very *local* concept informed by cultural discourses that inform the concept. While the concept of disability has many cultural and historical roots in the West and continues to be developed in this context, part of its history is that it has been exported and infused throughout the world where in turn it may have been adapted to local contexts. This is the process of the *globalization* of disability.

In a global context, it may be overlooked that all cultures of the world have developed conceptualizations of bodily difference. Professional disciplines have not been very successful nor very active in investigating cultural definitions of disability. Yet the articulation of both the local and the global seems to be at the very heart of the contemporary experience of disability. Global discourses of disability have not developed much cultural sensitivity to local understandings of disability. Local concepts of disability are expressed in a variety of ideas and practices that relate to persons, communities, and cosmologies. These ideas are expressed through language, artistic expressions, family and social organization and ritual, religious, spiritual, and cosmological ideas and practices. Ideas that inform practice toward people with bodily differences are also contained in concepts of human development, gender roles, and political discourse. Gaining an understanding of disability from an indigenous perspective may grow from an alignment with one or several of these expressions or ideas. Research on local concepts of disability has been extremely limited. There are many historical reasons in the colonial and post-colonial contexts, together with the appropriation of the field of disability to selected disciplines, and the dominance and overriding nature of globalization trends regarding disability, such as new practices or ideologies. There is an imbalance and a shortage of work that addresses local articulations of disability.

A CULTURAL THEORY OF DISABILITY

Theoretically, researchers have to overcome *universalistic* and *relativistic* understandings of disability. These paradigms do not adequately address the complexity of disability in cultural and historical contexts. Instead, researchers must find ways of addressing both. I have made an attempt to do so in two recent papers in which I argue that disability is an interstitial category, that is, people with impairments are situated (and situate themselves) in between the structural categories that define cultures. This is a universalistic claim that acknowledges that people with disabilities are the same and different, essentially culturally ambiguous. This claim is very different from a stigma designation of disability, with its stress upon the negative and marginalizing effects that result from disability. It is also different from the designation of disability as liminal, although I do not completely disagree with this designation (see Murphy et al. 1988). Instead, the interstitial nature of disability adds a structural component to the notion of liminality and does not imply people with disabilities are simply culturally suspended, devoid of any power. Instead, *interstitial* is intended to express the potential and the energy that results from a phenomenon that challenges and interrogates existing categories. It defines disability as a source of innovation and creativity. It also assigns some very real power of subversion of existing categories. It is obvious that these theoretical claims are rather empty without being substantiated with cultural material. This is where *relativistic* claims come into place. The interstitial nature of disability can be documented in linguistic arenas: e.g., the classification of disability terms in the Bantu noun-class system, the designation of persons with mental disabilities in English (feebleminded, mentally deficient, mentally subnormal, mentally handicapped, mentally retarded, etc.), social practices (e.g., marriage arrangements involving Bantu and Western women with disabilities), and in artistic, spiritual and religious arenas.

PROSPECTS FOR RESEARCH ON LOCAL CONCEPTS OF DISABILITY

How can research that strikes a balance between the local and global, indigenous and expatriate, relativistic and universalistic be developed? It appears that cultural richness and resilience is predicated on a healthy interdependence between these dimensions. Research can be instrumental in building a dynamic that no longer favors a pre-modern or a modern alternative but takes advantage of what was gained from both. In the area of disability, however, the medicalization, professionalization, and globalization of disability have generally ignored and oppressed local development and indigenous thought on disability on the basis that it could not meet the needs of disabled people nor of a colonial or independent nation state. In the process, the positive and constructive elements that local development and indigenous concepts contribute and continue to provide have been lost to policy and service providers. A cultural discussion is therefore needed to recover what has been ignored and to distinghuish the positive from the negative. Such an exercise would build cultural resistance and create a sound basis for interacting on a global dimension. In the remainder of this article, I would like to outline a rough plan of research to which social science and humanities oriented research can contribute.

Language

Language provides one of the most powerful tools for building a cultural understanding and critique of disability in the local context. Language informed research includes the historical and cultural analysis of concepts, proverbs, tales, narratives, and myths. They are the linguistic sediment of a culture's take on disability, they lead to an understanding of the meaning of disability itself, the use of disability as metaphor, the representations of disabled people and are an important aspect of the history of disabled people. Language is indicative of classification systems and directly leads to questions of social stigmatization and opportunities for social development. This increases understanding but also informs policy and practice that comes from the inside of cultures.

Art

Beauty and perfection are qualities that are expressed in all societies through art. The relationship between disability, beauty, and perfection is one that deserves attention because it impacts on the representation of disabled people. Indigenous ideas of disability may be influenced by cultural conceptions of bodily perfection and beauty and highly informative for understanding the consequences of living with disability in a given cultural context. Another aspect is the relation between disabled people and the production of art. How does art confront disabled people with their social status and the very private experience of disability. Does art play a conservative role or a transforming one?

Ritual, Religious, Spiritual, and Cosmological Ideas and Practices

Ritual transitions, religious sanctions and boundaries, taboos, sorcery, cosmogonies can reveal some of the deep meanings of disability that have developed as part of a cultural history. These ideas and practices are among the most powerful and resilient. They portray disability in the context of community in the largest sense of the word, including people, spiritual world, and all living beings. In addition, disabled people's access or lack of access to these ideas and practices define the cultural poverty or richness of their lives and the potential for transformation. Research in this area has been remarkably absent partly because of the Western cultural traditions in which disciplines that are concerned with disability have emerged. These disciplines have favored scientific models as the norm for knowledge production. However, the current research climate in the West, including the empowerment of disabled people, the emergence of their voice, and the response of interdisciplinary developments at the academy are promising developments.

Cultural Concepts of Human Development

Since disability is a phenomenon that manifests itself at different points of the life cycle such as fertility, birth, life transitions, old age, these ideas indicate a variety of tolerance toward human differences, the definitions of difference at various times of the life cycle. Considering the cultural meanings and role expectations at these different stages in life can add to our understanding that disability is not a monolith but variable within cultures.

Gender

The intersection between disability and gender is an important area of research. Cultural expectations of marriage arrangements, child bearing, family, occupation, employment, and career are very specifically structured in societies that additionally aim specific constraints and opportunities at disabled people along gender lines. The perspective of gender is methodologically important to show local variation of disability conceptualization within societies.

Political Discourses

Local medical and legal cultures contribute to the definition of the status of disabled people in society. These cultures operate as a result of political discourses that structure indigenous government, such as political offices, law, etc. responsible for the rules in societies that affect individuals with disabilities. In societies of the South, pre-modern political discourses, both gerontocratic and state oriented systems, have defined the very existence of disabled people. Colonial governments have been responsible for developing new structures and services that redefined disabled people. In the post-colonial and post-modern contexts, political discourses again define the local experience of disabled people.

Tools for Development

Research into local concepts of disability is to happen within disciplines, forums, and research avenues that promote the work that needs to be done. The development of an international association resulting from the conference (see Introduction) was identified as a primary goal to be pursued. Future communication mechanisms, such as a newsletter and a research journal, seem to be next on the list of priorities.

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TOWARDS A METHODOLOGY FOR *DIS*-ABILITY RESEARCH AMONG ETHNO-CULTURAL MINORITIES

Parin Dossa

The disability movement is a grass root level initiative drawing its early inspiration from civil rights issues raised by African Americans in the early sixties. Paradoxically, the movement's growth and development has not included cultural minorities. Multiple reasons can be cited for what might have been a natural affiliation. While it is common knowledge that it is advantageous for excluded groups to work together, this cannot be easily put into practice, as the constraints of the larger system loom large. In the case of Euro-American societies where a centralist state defines disability as a stigmatized category, marginalized groups are systematically kept apart and positioned to compete for scarce resources (for example, Ingstad/Whyte 1995; Bannerji 1984). Thus the emergence of an umbrella group working towards a common goal of equality and justice is rendered impossible and this accounts for the fact that the disability movement is separate and isolated from other civil rights organizations. The discourse implication of such a separation is that we use multiple words to describe the situation of marginal populations: *ethno-cultural*, *racialized*, *gendered*, *dis-ability*, *minorities*. The underlying grid of this terminology is that of the Other – not like us.

Racial minorities in North America and elsewhere have been engaged in an active struggle to transform a stratified system where skin color and gender make a significant difference in accessing valued social and material resources. Concerns surrounding persons with disabilities are cast in the same mold: their struggle for resources includes issues of personhood and dignity, as is evident in the gradual paradigm shift away from a *charity* model towards that of entitlement and citizenship rights. The underlying principle expressed is that disabled groups have the right to enjoy the quality of life and community participation that the able-bodied take as given. This again is due to the fact that the benefits enjoyed by the latter are built into the system, and they are thus not perceived as recipients of services. The struggle for equitable distribution of resources in a just society has other dimensions requiring further deconstruction. To begin with, the role of the state is central in defining populations as *problem areas* to be rectified through intervention strategies such as legislation and social programs. The state's power in shaping the environment within which persons with disabilities live and its control over distribution of rehabilitation goods and services makes disability into a business (Gritzer/Arluke 1987). In such a situation, those with vested interests provide services to those who are medically diagnosed as *dis*-abled. This form of political economic framing is sustained by ideological and sociospatial constructs. The *dis*-abled are further entrenched in the system through the powerful ideology of difference and Othering measured through hegemonic reference categories.

As disability and other forms of difference (race, gender, class) have been expressed in relational terms, reference categories come into play in different contexts. The question: "compared to what?" (Wolch/Dear 1993) leads to an understanding of disability as a measure of distance between the individual and the ideal of an *able* body. If disability is a statement about a person's deviation from a constructed *social norm* then we need to problematize the constructed and imagined spatial boundaries of difference. Within a broad spectrum of individuals with different physical and mental disabilities, the question that invariably arises is: at what point does any one person become *dis*-abled? (ibid.: 458) There cannot be a single identifiable point as any form of demarcation is contingent upon social and cultural expectations concerning established norms of work and appearance. It is apparent that we have not sufficiently problematized the relative nature of disability as well as those of *race*, ethnicity and gender. We frequently assume that we know who is able bodied and who is *dis*-abled and who is normal and who is different. Furthermore, the constructs of difference and normality are not absolute even within one social setting as varied criteria and norms are applied in differing contexts. Butterfield (n.d.) and Murphy (1987) observe that dominant implicit norms are used as reference points to evaluate and judge others distant from an implicit criterion. While this is true to a large extent, the implicit nature of the norm leaves room for negotiation and reconfiguration of imaginary and constructed boundaries. Value judgments about normalcy contain ambiguities embedded in specific spaces – an aspect that I will discuss below with reference to methods.

Before we engage in the discussion of methods, it is useful to ask what purpose does the drawing of imaginary boundaries serve? Western researchers have suggested that the impulse to distinguish between us and them, like and unlike, constitutes an integral part of representation. The formation of individual identity, for example, has been explicated in relation to the Other. Gilman (1988), among others, attributes the need for distinction to the wish to gain a sense of control:

> Difference is that which threatens order and control; it is the polar opposite to our group. This mental representation of difference is but the projection of the tension between control and its loss within each individual in every group. (ibid.: 458–459)

Preoccupied with the premise of difference, the Other's proximity and the transgression of socially constructed boundaries are taken as a threat to the well-being of individual identity because "they challenge the territorial position of the self" (Wolch/Dear 1993: 461). There exist powerful distinctions within our social landscapes which determine who can cross what boundaries, under what conditions, and at what times.

Once a dividing line is drawn between *dis*-ability and *able-bodied* and also along *race* and ethnicity, we encounter a situation of naming the difference, a process that assumes such an intensity that no non stigmatizing discourse exists for those who are labeled (Zola 1993). Western discourses on the variant *dis*-abled, racialized and gendered bodies have an epistemological grounding in colonial capitalism that we are only beginning to understand in all its complexities. While we cannot underestimate the power of sociospatial relations and ideology in the construction of difference and marginalization of the Other, this is only part of the analysis constituting the systems approach dominant in the seventies and eighties. Human action and agency provide invaluable insights into resilience, negotiation and remaking of life worlds. Realizing the loss of this dynamic, Anthony Giddens (1985) has dubbed the relationship between structure and agency one of the central problems of modern social theory. Theoretical and methodological insertion of human agency into structure has taken varied forms salient among which are: 1. life narratives and stories; 2. space; and 3. embodiment. These critical approaches are of special value in the study of racial (ethnocultural) minorities with disabilities as they enable us to move away from the dominant victimization mode, where *culture* is reified and frozen in time and place, towards embodied social agency.

Towards this end, I discuss some methods that lend themselves to identifying agency and its interpolation into structure (as part of a continuum). The methods are exploratory in nature and are presented to invoke discussion. The following should therefore be taken in the spirit of sharing of ideas rather than a systematic study. The objective is to invite others to further experiment with non conventional modes of research.

LIFE NARRATIVES AND STORIES

The genre of narrative/story posits the presence and voice of the subjects of research. In taking note of detailed accounts omitted in positivist approaches, it captures the humanity of individuals who otherwise have been rendered socially invisible. The narrative genre has been found to provide a medium for understanding of cultures (as lived reality and therefore in flux) as it permits greater collaboration between a researcher and the subjects. More recently, a narrative approach has been utilized to capture the way in which medical and other systems impinge on and impact on individual/family settings. The narrative genre then does not lend itself to a coherent and polished synthesis where contradictions are dismissed. Rather, a recurring theme is one of multi-stranded connections of people, places and events – a scenario that defies strict confinement within the unit of one dominant discourse. Through narratives, one does not only have an appreciation of what it is to be human but also of how one's humanity is played out in the dynamic interplay of disability, gender and *race*. The core concern is not that of mere construction of narratives, but subtleties of change between disparate worlds: the intricate interface between discourse on the medicalization of *dis*-abilities (construction of the variant body, process of *labeling*, politics of social services) and non-medicalized interventions and life aspirations. The point being that narratives of the ethno-cultural minorities capture experiences and provide insights into processes that include triple social constructs (*disabled*, racialized and gendered) and their reconstitution by subjects.

> Life stories have been defined as testimonials, a process of struggling towards a particular consciousness, that both reinterpret and remake the world. (Ong 1995: 354)

Narratives of minority persons with disabilities reveal the different ways in which they negotiate socially constructed labels of Othering and claims to subjectivity (Dossa forthcoming). The following outline serves to contextualize this further.

1. The telling and listening paradigm of narratives (Ong 1995) has the effect of lessening the personal and pedagogical distance between the

narrator and the researcher. The resulting double-voiced discourse captures the speaking subject's perspectives and that of the listening subject's location in research. The dialogue between the two voices can be extended to include the reader. It is within such dialogical encounters that alternative perspectives may be identified.

2. Recording of narratives serves a therapeutic purpose. As individuals begin to understand their own experiences informed by multiple constructs (*dis*-abled, racialized and gendered), ideological underpinnings come to light. This process reveals a deeper understanding of historical and *cultural* constructions of social categories – the first step towards effective change and transformation.
3. From a research perspective, the narratives contain invaluable data on the overall social history of an epoch. In the case of ethno-cultural minorities with disabilities, contradictions of social politics, immigration policies and experiences of *race*, *dis*-ability and gender emerge as part of historical and social developments. Ethnocultural minorities may have been subject to colonial and postcolonial legacies; some may have come as refugees and many are subject to compounded forms of negative labeling. Interrelationship between *dis*-ability experiences and *race* and culture can then be explained reflexively within the overall social history of a particular period.
4. Other than the individual and consciousness raising dimensions, the recording and discussion of narratives point to action-based and policy orientations. The rich and touching elements of narratives provide an impulse for mobilization and activism. This form of shared consciousness allows one to transcend isolated horizons for a common cause.
5. Life narrative data challenge hegemonic perceptions of ethnocultural minorities as victims forever struggling to overcome numerous constraints. Alterity and other ways of being encoded in narrative data provide a much-needed critique on social inequality and injustice.

FORGOTTEN SPACES, (RE)MEMBERING LIVES

In recent times, critical social theory has advanced the framework of the social construction of space for the understanding of *race*, ethnicity and gender; yet there is a paucity of data (with the sole exception of physical environment) on how multi-layered spaces impact on the lives of people with disabilities. While this in some ways is a reflection of the intense marginalization of persons with disabilities, this oversight ultimately relates to the fact that social and physical spaces are constructed for able-bodied individuals where white, middle class males fare well (Wendell 1996). The non-existence of *spaces* for those who are *dis*-abled further isolates their conditions and experiences. We have not as yet developed spatial discourses that provide insights into how societal values, practices and structures impact on lives (Soja 1989). That space has much to do with multiple marginal positioning of ethnocultural minorities with disabilities may be demonstrated by drawing cues from critical geographers, as well as cultural and feminist anthropologists (Dyck 1995; Kerns 1997; Emberley 1993; Fine/Asch 1988; Minh-ha 1989). These critiques suggest that space, and its concomitant place and also time, cannot be delineated within a unitary framework. Spaces are gendered, *raced* and disabling both in their representations and how they are experienced. Dyck (1995), for example, has shown how women's work evokes spaces that are not legitimated in dominant representations. A focus on everyday space(s) of home, streets, neighborhoods and work reveals complex interdependencies that challenge dichotomous representations of pubic and private, and productive and reproductive spaces. The point that needs emphasis is that actors remake and bring specific meanings to different spaces as they experience them.

Given the centrality of space in human experience three distinctive dimensions of space may be identified to advance the interests of ethnocultural minorities. First, members of cultural minorities have themselves undergone spatial changes of (dis)placement, as they have moved physically from one geographical area to another. In their new location, spatial categories are reworked and subject to configuration giving rise to networks and identities as individuals interact in new and emerging contexts; cultural and/or sacred spaces form part of this complex as ethnocultural minorities interact with one another and with the larger community. Social interactions include *physical spaces* of residence and construction of physical buildings (community organization or a place of worship) as well as other urban spaces: streets, neighborhoods and shopping malls. Thus an emphasis on space allows us to explore the cultural and religious practices of minorities beyond the articulation of elites towards the everyday practices of ordinary people. Spaces of everyday life situations are replete with meanings and nuances integral to understanding situations of disabled persons from ethnocultural backgrounds.

Second, visual clues and more tangible aspects of spatial organization are easiest to identify. Canadian Muslims with disabilities, for example, often symbolically expand the spaces of their bedrooms in residential and institutionalized settings with rosaries, the Qur'an, recitation tapes and calligraphic engravings (Dossa n.d). The visual is easier to accommodate so far as it remains within the private space of the *resident*. Its display in the living room or lounges would be problematic as it would take up the space of more dominant and apparently neutral representations. While one can argue that artistic and/or consumer items form part of the way of life in the host country, these items do not necessarily reflect meaningful and historical experiences of ethnocultural minorities with disabilities. By and large, visual clues within group homes or institutional settings, neighborhoods or streets do not convey a multicultural landscape. For minority persons with disabilities, the minimal existence of expressive spaces may translate into social barriers that are not addressed within the popular discourse on community integration.

An overlooked and third spatial dimension of ethnocultural minorities is that they form part of communities that live globally on multiple sites. This connection to a diaspora foregrounds spatial overlapping transcending national boundaries in intricate ways. Constituted space of this nature may be conceived in the form of an imagined life that contributes to moral and ethical discourses that touch on fundamental issues of *what makes us human*. The service delivery system can benefit from the ethically informed constriction of space. The grounding of the former within the political economy is not conducive towards promoting humane perspectives, as these come to light through the spatial construction of reality. Re-mapping spatial landscapes to include insights from the diaspora (other ways of being) brings us closer to being-in-the-world – experiencing it with mind, affect, emotion and the body. This point takes us to the third method of embodiment.

EMBODIMENT

An excerpt from the life narrative of a Canadian immigrant family from Uganda captures some of the questions addressed under the rubric of embodiment.

> Every day before going to work (Mwanza), I (Khatoun) carried my disabled daughter (Razia) from my house to my mother-in-law's house for six years. Here (Canada), every Saturday, we pick up Razia

> from her group home and take her to McDonalds for lunch before she visits us for the weekend.

These two sentences from Khatoun's life narratives bring into relief spatial location/dislocation of a *dis*-abled body. What are the conditions that lead to Razia being cared for at home in one country and being able to utilize social services in another country? How is the border crossed from home care to social service care and what are its implications for people whose very existence has been questioned by society? What kind of meaning does disability have in different cultural settings? These questions inform retelling a life lived at certain historical moments that involve cross cultural encounters, encapsulated in the image of the body. The latter is of interest for two reasons. First, contemporary scholarship in human sciences regards the body as a site of contestation, control and management, as revealed in the image of a medicalized and consumerist body (Falk 1994; Featherstone 1982; Featherstone et al. 1991; Foucault 1979; 1980; Lock 1993). Second, consideration of representations of the body in Western society is necessitated by the fact that the Western hegemonic discourse of the body is transposed to ethnic and *disabled* bodies. The conception of the body implicit in these representations postulates the body as passive recipient of subordinating forces. These impulses render a partial understanding of the engagement of the body in complex spaces; while it may be defined by the needs of hegemonic systems, the body establishes points of intervention to reveal human agency at work. An appropriate and promising line of inquiry is that of embodiment, that is, the being-in-the-world of struggle, negotiation, and reconfiguration of life where affect is an important component. The body's engagement with the world in terms of *embodied sociality* and the role of affect through which "individual bodies together with others articulate a common purpose, design or order" (Lyon/Barbalet 1994: 48) needs more emphasis. For persons with disability, the linkage between affect and the social cannot be assumed as the possibility of disjunction is very real. In a situation where the condition of disability includes gender and ethnicity, the disjunctures and reconstruction of lives may include the crossing of multiple borders. The method of embodiment lends itself to apprehending this multi-faceted phenomenon.

The body and its praxis of embodiment as a way of being-in-the-world is given little conceptual space. The epistemological foundation of the medicalized consumerist body can only be challenged with the view that

> we do not have bodies, we are our bodies and we are ourselves while being in the world ... we write – think and feel – (with) our entire bodies rather than only (with) our minds or hearts. It is a perversion to consider thought the product of one specialized organ, the brain, and feeling that of the heart. (Minh-ha 1989)

Appreciation of embodied praxis requires that we pay more attention to interactive, relational and social aspects of the body together with affect. In the depiction of the body as social and as engaged in the making of meaning, it is hard to conceive of the body as being only passive. The tension between having bodies (the underlying base of the consumerist and medicalized gaze) and being bodies (interactive aspect of self) may be addressed through affect. The latter can then be conceived of in relational terms. It follows then that

> social relations implicated in emotional experiences involve the body: not simply the body as a physical entity subject to external forces, but the body as agent. (Lyon/Barbalet 1994; also refer to Csordas 1994; Frank, A. 1991; Frank, G. 1984; Lutz/Abu-Lughod 1990; Lutz/White 1986)

Affect has its foundation in sociality; its location within the body forms the basis of embodiment.

The question of what it means to be human – an unrealized anthropological quest – continues to remain submerged, as we have not focused on methods that allow a sustained inquiry on this important subject. The methods suggested in this paper lean more heavily towards social agency. I remain convinced that it is through this channel that we can (re)gain the ability to go beyond a situation and connect with life worlds, which through their very difference, encapsulate central questions of existence. Hermeneutically open *texts* generated from non-conventional modes of research constitute one way of connecting. After all, it is only through the discovery of common ground that we can engage in embodied praxis where socially constructed distinctions and boundaries become less significant. If this appears to be a utopian image, the alternative discourse of Otherness is paralyzing.

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DISABILITY RESEARCH IN CULTURAL CONTEXTS: BEYOND METHODS AND TECHNIQUES

Kofi Marfo

INTRODUCTION

The invitation to participate in the *expert* meeting on disability research (see Introduction) came at a time in my career when I see myself more as a student seeking to gain a better understanding of the history and culture of the research enterprise so that I can increase the relevance and meaningfulness of my own research and become a better teacher and research mentor for my students. Over the past few years, I have come to characterize my excursions into the sociology and philosophy of science as a quest to develop deeply personal understandings of the ethical and professional responsibilities associated with the researcher role. I hope that the issues I have chosen to address in this working paper will not be deemed too esoteric to be relevant to our discussions in Bonn, because I think a meeting on disability research in cultural contexts is a most authentic forum for a discussion of these issues. The timing is auspicious too, given the ascendancy of the paradigm dialogue in a number of disciplines.

The central premise of this paper is that research/inquiry is not a value-free enterprise. All researchers walk into the arena of inquiry with baggage. Embedded in this baggage, among other things, are the effects of one's own cultural background on the way one views the world, the impact overt or covert of specific social and/or political processes or events that often provide the impetus for specific lines of inquiry, the impact of formally acquired paradigms of inquiry, and the biasing influences of specific conceptual frameworks within a chosen paradigm. In this paper, considerations of the ever-present influence of these forces on the inquiry process are subsumed under the general rubric, *philosophical and socio-cultural underpinnings of inquiry*. With the foregoing as the central premise, this paper seeks to develop the position that no meaningful discussion about research can be deemed to be complete unless it includes examination not only of methodological and technical issues but socio-cultural and philosophical issues as well. While I consider this position to be axiomatically applicable to discussions of all types of research, it is particularly central to a discussion of research that takes as its starting point the quest for cultural understanding and relevance. To initiate the discussion, I present two specific themes. The first highlights the chasm between philosophical and methodological considerations in scholarly work on inquiry. Recognizing that understandings about, and responses to, *cultural difference* lie at the heart of culturally contextualized inquiry, the second theme focuses on the importance of researchers' self-reflections about their personal constructions of *difference* as a precondition for meaningful inquiry.

ON THE CHASM BETWEEN PHILOSOPHY AND METHODOLOGY

Let me cast the introduction of this issue in the context of a challenge we encounter frequently in debates about the dearth of indigenous contributions to the knowledge base of cross-cultural research. To take an example from the field of psychology, it has been remarked that much of the scanty research knowledge on human development which represents the work of indigenous African investigators is largely unpublished, and contained mostly in theses and dissertations completed in fulfillment of requirements for the award of university degrees (Nsamenang 1992/ Serpell 1984). Conversely, much of what is published and, thus, easily accessible about psychological development in the African context appears largely in foreign sources and tends to represent the work of itinerant Westerners etc. whose mission has usually been to test Western theories on strange populations or to explore exotic cultures (Nsamenang 1992: 14). This is perhaps an observation that can be extrapolated fairly to the state of research knowledge on disability and culture as well. The connotation, in both instances, is that expatriate researchers' dominance over the production of knowledge in indigenous cultures is problematic because the images portrayed about indigenous people, their beliefs and practices, are bound to be colored by the culture-constrained values, biases, and interests these outsiders bring to the issues they study. By implication, increasing the role of indigenous researchers in the production of knowledge is expected to increase the ecological validity and relevance of such knowledge.

But the problem is not just one of expatriate researchers filtering indigenous conceptions and practices through the dark lenses of their own cultural heritages. A close examination of social and behavioral science research by indigenous scholars in their own cultural contexts will probably reveal a significant, if not preponderant, tendency toward replication studies designed to assess the *universal applicability* of conceptual and empirical models or specific hypotheses tested originally in the industrialized world. That is, given the opportunity and resources, indigenous scholars may not approach the cultural content of social and behavioral science research any differently than the so-called itinerant expatriate investigators. This reality underscores my position that scapegoating expatriate researchers and their scholarship for the paucity of bodies of knowledge that reflect adequate regard for and informed understandings of indigenous cultures is not a productive exercise.

Part of the key to understanding the shortcomings of research relative to the importance of cultural contexts is understanding the *history* and *culture* of inquiry itself. I do not intend to offer an elaborate thesis on the nature of inquiry (I am not even sure if I am the right person to do so), but I do want to lay out some basic ideas to stimulate further discussion. At the barest minimum, inquiry has two components: *philosophical* and *methodological*. The philosophy of inquiry can be further categorized into *ontological and epistemological* considerations. The ontological consideration deals with the nature of the knowable or the nature of reality, while the epistemological addresses the nature of the relationship between the knower (the inquirer/researcher) and the knowable (Guba 1990). Methodology, of course, deals with *how* the knower goes about finding out knowledge.

Table 1: Elements of the Philosophy of Inquiry
Based on Guba (1990)

Element of Inquiry	Associated Questions
Ontological	What is the nature of reality or the knowable?
Epistemological	What is the nature of the relationship between the knower and the knowable?
Methodological	How should the knower go about finding knowledge?

Embedded within all paradigms of inquiry are ontological, epistemological, and methodological questions. There is a good analogy here between culture and paradigms of inquiry. Much as members of any given culture are distinguishable from members of other cultures by the beliefs, values, language, and practices engendered by their own culture and transmitted through the socialization process, researchers operating from any given paradigm of inquiry are distinguishable from other researchers by the beliefs and assumptions or presuppositions they have been socialized to hold about ontological, epistemological, and methodological issues. These beliefs and assumptions frame the questions researchers pose, determine the phenomena about which questions are posed, and dictate the methods and procedures with which data are obtained, analyzed, and interpreted.

Of special pertinence to our discussion here is the suggestion that matters of ontology (the nature of reality) and epistemology (the knower-knowable relationship) are exactly what set one culture apart from another. Cultures tend to impose different value systems and different ways of knowing and relating to the universe, such that what is meaningful and valid in one culture may not necessarily be so in another culture. From this perspective, inquiry is intrinsically a cultural activity. It is a search for knowledge through culturally-determined ways of knowing. It begins with cultural conceptions and should end with outcomes that have cultural relevance. The researcher who misses this central principle misses the very essence of inquiry. This perspective raises some fundamental questions for the researcher: is the validity of culturally contextualized research threatened by ontological and epistemological differences in the worldviews of the researcher and the participants of the research? What steps can be taken to mitigate this potential source of threat to validity? Paradoxically, the answers to these questions are rendered more complex by the reality of increased cultural contact and exchange. The Western education model dominates the educational systems of the developing world, and the formal research training of indigenous scholars continues to take place largely in the industrialized world. Consequently, as implied in an earlier comment, the ontological and epistemological perspectives with which the indigenous scholar approaches research in the local context may not be any different from those with which the expatriate scholar approaches research in a foreign cultural context.[1] The point of this caveat is that in answering the two questions posed above, we must avoid the simplistic tendency to separate indigenous and expatriate scholarship, as if they are informed by substantively different mindsets. Regardless of our cultural identities, too many of us think of research more in methodological terms than in philosophical terms. Examining our own beliefs, assumptions, and biases about the phenomena we study, the questions we pose, how we pose them, and the individuals from whom we derive our data is not a well established part of the research process in many disciplines. Cultural anthropology is perhaps an obvious exception. The divorce of philosophy from methodology manifests itself across many disciplines. If this is deemed to be problematic in the natural sciences, it is even more so in the social sciences and the humanities where the problems that researchers seek to address are embedded intricately within the complex social, political, and moral fabric of a given culture. However, all too often what passes for good research in the social and behavioral sciences is judged on the basis of methodological rigor and the elegance of the empirical analysis. As can be gleaned from the paradigm debate currently raging in many fields, this divorce of methods and evidence from philosophy and social processes is seen as one of the central weaknesses of the empiricist tradition within positivistic science. In social and behavioral science disciplines which have been under the strong influence of the natural science approach to inquiry, e.g. psychology, sociology, family studies and rehabilitation psychology, graduate-level research training tends to overemphasize methods and techniques of designing research and collecting and analyzing data at the expense of the philosophical, socio-cultural, and moral issues that underpin or are associated with both the research question and the methods and procedures selected to address it.

If the divorce of method from philosophical assumptions and values is problematic for the pursuit of research in the context of industrialized societies, its ramifications for knowledge production in non-industrialized cultures is arguably more profound. The criteria of relevance and meaningfulness require researchers to be sensitive to the importance of framing research questions and selecting methodological tools with due attention 1. to the content and context of the culture and 2. to the researchers' own understandings and assumptions regarding the culture. This is as true for the indigenous investigator as it is for the expatriate researcher. Until research training programs begin to pay sufficient attention to the philosophical, social, and moral dimensions of inquiry, the graduates of such programs will continue to be ill-prepared to pursue culturally relevant research within indigenous contexts.

THE RESEARCHER'S PHILOSOPHICAL MIND-SET VIS-A-VIS CULTURAL DIFFERENCE

Let us examine the importance of philosophical issues in the pursuit of inquiry from another angle. Conducting inquiry from a culturally contextualized perspective entails constant comparisons of value systems, ideas, and practices. Such comparisons are often between the researcher's own beliefs, values, or practices and those of the culture under study (as is the case with expatriate researchers or with indigenous researchers examining two subcultures within their society, one of which is their own). However, comparisons may also involve two cultures or subcultures that are neutral to the investigator. Each one of these instances requires critical reflection on the part of the researcher about her/his own beliefs and attitudes about *cultural difference*. The *subjective self* is very much a part of the research process. This point is very important because while we often do not acknowledge it: the biases we bring to the research process as a function of our own comparative mind-set do impact the outcomes of our research. How does the researcher respond to ideas, beliefs, and practices of others? How do the subjectively held perspectives of the researcher affect the conclusions drawn from inquiry entailing cultural comparisons?

The work of comparative anthropologist Richard Shweder (1991) offers some useful insights into the manner in which different interpretive models lead to differences in the way we view and appreciate the understandings, beliefs, and practices of other peoples. Shweder describes three interpretive models for making sense of *difference*: universalism, evolutionism, and relativism. Universalists are individuals who view diversity as more apparent than real. To them, alien idea and belief systems are really more like our own than they may appear. In search of universals in apparent diversity, universalists emphasize general likenesses and overlook specific differences. To evolutionists, not only are alien idea or belief systems truly different; they are different in a very special way. Evolutionists view alien idea and belief systems as "really incipient and less adequate" (ibid.: 114) forms of their own idea systems. The evolutionist's view reflects a hierarchical organization of idea systems, embedded in which is a three-stage rule. Confronted with diverse idea systems, evolutionists will 1. locate a normative model, 2. reify the evolutionist's own idea system as the normative model at the end or highest point of development, and 3. describe the diverse idea systems in a hierarchy going from the more primitive toward the normative model.

In contrast to universalists and evolutionists, relativists hold the viewpoint that while alien idea systems differ fundamentally from our own, they do display an internal coherency that can be understood but cannot be judged (ibid.: 114). Faced with apparent diversity of human understandings, then, relativists seek to preserve the integrity of the differences and establish the coequality of the variegated forms of life (ibid.: 119). They do so by contextualizing the differences. Contextualization entails searching for and presenting more details (e.g. the objectives, premises, presuppostions, standards, etc.) that make it possible to see the meaning in the otherwise apparently incomprehensible. Thus, in the words of Shweder, relativists are inclined to *think through* the idea and belief systems of other peoples and their cultures as they seek to understand both their own minds and the minds of the peoples they seek to understand. Table 2 summarizes the key attributes and slogans corresponding to each of the three models.

Table 2: Interpretive Models for Understanding Alien Idea Systems
Based on the work of Richard Shweder (1991)

Model Slogan	Key Value and Attributes
Universalism	*Homogeneity*: diversity is “Apparently different but sacrificed for equality really the same”
Evolutionism	*Hierarchy*: diversity is not “Different but only tolerated; it is expected and unequal”
Relativism	*Pluralism*: equality *and* “Different but equal” diversity as a democratic aspiration

Assuming that Shweder’s interpretive models are both exhaustive of the ways of viewing difference and are mutually exclusive at the same time, what would it mean for a researcher to characterize her/himself, upon self-reflection, under any one of these models? How differently would each mind-set affect what the researcher chooses to study, how it is studied, and how the outcomes of the study are interpreted? To acknowledge the potential differential impact of these (or any other) interpretive modes on the various dimensions of the inquiry process is to underscore the centrality of philosophical considerations. This kind of reflection is hard work and perhaps even risky, not only because of its potential to reveal perspectives and orientations that may be hard to acknowledge but also because it can lead to the superficial adoption of politically correct orientations.

SOME PRACTICAL PROPOSALS

1. Build coalitions of international (expatriate) and local (indigenous) research and service professionals and promote ongoing dialogue on research and practice in cultural contexts.
2. Articulate clear values about research, with equal attention to methodological and philosophical issues, and with deep respect for multiple approaches to inquiry.
3. Promote a *multidisciplinary* and *multiparadigmatic* journal on disability research in cultural contexts, with a broad-based editorial board consisting of 1. researchers, practitioners, policy makers (including individuals with disabilities at all levels) and 2. international and local professionals. Use the journal not only as a forum to disseminate original field research but also as a place for ongoing dialogue on philosophical, socio-cultural, ethical, and methodological issues in research.
4. Promote linkages between research institutions in industrialized and developing countries.
5. Support institutions in developing countries to develop research training programs which emphasize culturally contextualized inquiry.

NOTES

1 This comment is not in any way intended to suggest that indigenous scholars are incapable of *thinking through their own cultures*, to borrow the words of Richard Shweder (1991). However, it is naive to distinguish between indigenous and expatriate scholarship purely on the basis of the scholar's *surface* cultural identity.

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SOME THOUGHTS ON DEFINITIONS AND A METHODOLOGY OF CROSS-CULTURAL RESEARCH PERTAINING TO DISABILITY

Arthur Vreede

INTRODUCTION

In 1993 I set myself the task of compiling a bibliography of indigenous concepts, attitudes and practices regarding physical disability. While a lot of literature was found on related issues, the combination of the keywords *indigenous concepts* and *physical disability* turned out to be very unproductive. The majority of the literature consists of results of surveys on attitudes towards persons with a disability (PWD). Very few in-depth studies were found. Among these may inter alia be counted the studies by Stiker (1982), Burck (1989) and contributions in the books by Bruun and Ingstad (1990) and Ingstad and Whyte (1995). Besides in-depth studies, some articles are to be found which deal with the subject in a qualitative way, e.g. the articles by Scheer and Groce (1988), Ingstad (1988, 1990 among others), Walker (1981, 1986) and some contributions in monograph 53 of the IEEIR.[1] Many of these authors have stressed the fact that there is still little known about concepts and perceptions of disability, particularly on a local level, and that more needs to be done. Benedicte Ingstad (1995) for example has called attention to what she calls *real life situations*. It is necessary to investigate concepts and beliefs relating to disability and the disabled in their actual context.

The apparent lack of knowledge about concepts and beliefs regarding disability in different cultures and the ways these are interconnected with customs and practices on a community level was one of the reasons for organizing an expert meeting of researchers focused on cross-cultural research regarding disability. This expert meeting took place in Bonn alongside the symposium (cf. Introduction) and those present discovered that three days of discussion is hardly enough even to get an overview of bulletpoints for discussion and to discuss them very briefly. Agreement was reached to keep on talking, to found an international association for cultural research on disability and to reconvene in two years. In this article, which was originally intended as a working paper for the expert meeting, some viewpoints are put forward regarding research on the subject matter at hand taking the DL-concept (DL = daily living, see annex) as a starting point. Firstly, definitions of disability which are deemed suitable for practical purposes of field research are discussed. Secondly, suggestions are made for a methodology of research.

DEFINITIONS

In the context of rehabilitation, the use of the International Classification of Impairments, Disabilities and Handicaps (I.C.I.D.H.), is well known.[2] Many researchers feel that this *impairment-bound* model does not meet their requirements for field research and analysis.

The following criteria for a researcher's definition are proposed: can the definition:

- be applied in various cultural contexts (as a tool for analysis).
- describe or make intelligible local concepts of disability in the idiom of the researcher.

It would furthermore be useful for the research to be able to describe the researcher's definition in a local idiom, but this is not a necessary criterion. A preliminary definition of disability is proposed here, one that is context-bound, i.e. which is related to the actual activities of daily living (ADL) in a given community; or, to be more precise, ADL (activities of daily living) that are considered usual and necessary activities in that community.[3] Usual activities refer to prevailing norms and habits and these may differ greatly from one community to another; necessary activities are activities which have to be performed, regardless of whether one likes them or not: thus, bathing may be a painful activity for a person suffering from arthritis, but still be a necessary daily activity. Preliminary definition: a disability is a disturbed ADL (where ADL are understood as usual activities and are thus culture bound). Otherwise formulated: a disability is an inability to perform a *usual* activity (according to the prevailing norms).

Such a usual-activities-oriented concept, instead of an impairment-bound model, has obvious advantages for research purposes, such as the making it possible to distinguish between mere in-abilities (a general designation) and specific dis-abilities. Moreover, a usual-activities-oriented definition provides a strong incentive to first ascertain the *normal*, before focusing on disabilities proper. An expatriate surgeon who went to Uganda first travelled the country for one year before performing any operations (Baine 1965). Because ADL vary from one culture to another, concepts of disability also differ from one region to another.

INTERMEZZO

Usual activities (ADL) are based on physical/mental functions and structures (ODL) and they are motivated by personal/social purposes (IDL). The actual form that usual activities take is dependent on contextual factors such as: where is the activity performed (place), at what time (period), and in whose presence (persons)? Although the activities of daily living are experienced as usual and one's own activities from the perspective of the (local) performers, they may appear alien to outsiders. Local people may not bother about mere inabilities, whereas disturbances of usual activities (i.e. disabilities) may have important consequences. An in-ability becomes a dis-ability (disturbed ADL) only if the inability leads to a hindrance in performing usual activities. Compare the following examples. (A disturbed IDL may be equated with a handicap, a disturbed ADL with a disability and a disturbed ODL with an impairment). Examples (simplified): A person afflicted with a refraction anomaly of the eyes that would prevent the person from reading without glasses.

When in an illiterate context:
- has not got a disturbed ODL
- has not got a disturbed ADL
- has not got a disturbed IDL

When in a literate context, but unable to read:
- has got a disturbed ODL
- has got a disturbed ADL
- has got a disturbed IDL

In a literate context, able to read with glasses:
- has still got a disturbed ODL
- has not got a disturbed ADL
- has not got a disturbed IDL

N.B. If the glasses are broken:
- has got a (temporarily) disturbed ADL
- may have a (temporarily) disturbed IDL, unless it is time to relax

A person with no anomaly of the eyes, but unable to read (never learned to read) – in an illiterate context:
- has not got a disturbed ODL
- has not got a disturbed ADL
- has not got a disturbed IDL

In a literate context:
- has not got a disturbed ODL
- has got a disturbed ADL (outside view)
- may have a disturbed IDL, depending on how personally experienced. In some remarkable cases, the person wears empty glasses, pretending to read, but holding the book upside down.

METHODOLOGY OF RESEARCH

In what follows it is taken for granted that the researchers want to know more about local concepts and beliefs pertaining to disability and the disabled. Statements for discussion:
1. a usual-activities-oriented approach (ADL-investigation) is an appropriate method for research on indigenous concepts and beliefs regarding disability.
2. research tools: to those of modern anthropological research (mentioned by Patrick Devlieger [p. 297ff.]) may be added:
    - intervention trials to establish a scaling of priorities (= most preferred IDL)
    - nicknames
    - seeming contradictions

ad 1: ADL-investigation is simple and accurate: observe and record the actual activities. Just note down very precisely: what is done, where, by whom, how, when, in whose presence. In short, the contextual factors (period, place, persons, product and performance in the idiom of the DL-concept) are recorded as well. Observations (and interviews) don't have to be focused on the disturbed ODL (impairment). On the contrary, the daily life of the community as a whole is studied. After having acquired a general picture of the ADL, attention can be focused on concepts and beliefs pertaining to disability. Using the definition of disability proposed here, this would imply the question: when is an inability considered a disturbed ADL? In other words: which inabilities lead to a hindrance in daily life? The advantage of this kind of investigation is that it can be applied in different cultural settings and that activities are studied within their actual context. Indeed, all the contextual factors mentioned above, as well as the other dimensions of the DL-concept (see annex), are inherent in any activity of daily living. At the same time this is a good opportunity to test the usefulness of the researcher's definition. The researcher may even try to falsify his or her definition from an inside perspective on the local culture. Last, but not least, the researcher may investigate personal experience in terms of the life satisfaction of the persons he/she is interviewing, using the ADL-approach as a method of research.

ad 2: priorities refer to most preferred purposes in daily life (most preferred IDL in the language of the DL-concept). These purposes or IDL, which relate to highly valued activities, may be scaled by using intervention trials, which present realistic and mutually exclusive choices, as a method of research. The scaling of IDL is valuable information for the personnel of rehabilitation projects, because it bears relevance to the experienced quality of life of persons with a disability. For example: market vendorship, having children and worship may all be IDL. The most preferred IDL, however, e.g. market vendorship, is the one at which the rehabilitation intervention should be directed. If the person concerned prefers to perform her work while squatting, the rehabilitation intervention is directed at this position. This may imply, as is true for all rehabilitation interventions: no intervention at all. So, besides an ADL-investigation, study of IDL should also be part of the research.

EPILOGUE

The relationship between 1. researchers on disability, 2. people responsible for the planning, funding and execution of projects and 3. organizations of persons with a disability is not well developed. I believe that a co-operation between these three parties would be fruitful for the well-being of persons with a disability. It indeed seems that many Northern-based NGOs think that they manage well enough without being well-informed about the needs, beliefs and ways of life of the community members. The kind of ADL-research that is proposed in this article is transcultural in nature in the sense that activities of daily living are regarded as culture-bound. Persons who have knowledge of both disability issues and local cultural backgrounds have been until now very seldom engaged in rehabilitation projects. The need to involve transcultural experts on disability (be they rehabilitation anthropologists, transcultural doctors, researchers, either disabled themselves or not) is obvious when one hears the stories told by expatriate rehabilitation workers.

ANNEX: THE DL-CONCEPT

What follows are quotations from *A Guide to ADL, the activities of daily living,* Eburon Delft, C.F. Vreede ed., 1993.

The Facets of ADL

The term *activities of daily living* can be more precisely defined by breaking it down into three facets. The facets constitute the first dimension of the structure of ADL. Moving legs, walking and going to the market represent three levels of the very same daily performance of an imaginary woman. These three levels can be labelled ODL, ADL and IDL, respectively. The highest level, IDL, implies a purpose: to go to the market (to sell her products); the middle level, ADL, implies an intention: to walk (to go to the market); only the lowest level, ODL, may be considered quasi-automatic: to move her legs (in walking).

Definitions

ODL (Operations for daily living) denote the physical or mental functional exertions and appearances applied in ADL, insofar as they can be performed or experienced consciously, although in practice this need not always be the case. For example: bending knees; moving one's hands; skin colour; staring.

ADL (Activities of daily living) denote the actual intentional activities usual to an individual or group of individuals. For example: squatting; throwing at a target; different bearing when in uniform; concentrating on a subject.

IDL (Ideas in daily living) denote the pursuits which subsume a value or common social purpose, in so far as they are described concretely and can therefore be analyzed in terms of ADL. For example: being a market vendor; playing marbles; dressing up in order to impress; listening to music.

This three-tiered concept of usual exertions, activities and pursuits constitutes a hierarchical system. An ADL *can* not be performed unless the required ODL are available, and *will* not be performed unless it forms part of an IDL. Moreover, ODL, ADL and IDL form a set of subsystems of increasing complexity, for an IDL always comprises several ADL, and an ADL in its turn comprises several ODL. The concept of a multi-dimensional structure of ADL will be denoted by DL. Thus, this DL concept also includes the two dimensions discussed below.

The Components of ADL

An ADL always takes place within a given context. The context or specific occasion within which an activity takes place is determined by a combination of components which we call the five P's: *performance*, *product*, *place*, *period* and *persons*. The components are inherent to ADL; together they constitute the second dimension. Note that period may either be a particular point in time, or it may refer to the duration of a period. Persons refers both to people who are present and to people who are conspicuous by their absence. Performance and product have been considered constituent components of ADL ever since the term was introduced. The importance of place, period and persons has not, however, received much attention. The fact that these three P's are inherent components of any ADL can best be illustrated by taking a closer look at the Korsakoff syndrome. An individual suffering from this disturbance, which may develop after prolonged alcohol use, becomes disorientated as to time (read period), place and persons, and may indeed innocently pass water in a crowded room at a party, which no-one in his right mind would do. Thus, this cerebral dysfunction results in a loss of decorum – and hence in a degradation of ADL. Conversely, any proper ADL implies these three components in addition to performance and product.

The Aspects of ADL

An activity which is a usual daily performance for a particular person may be strange to another individual. It therefore appears necessary to make a formal distinction between what is felt to be usual, or own, and what is considered unusual, or alien. As we have done in the foregoing, the distinction between own and alien will be represented by a terminological abbreviation, namely A (mere activities) for alien; whereas ADL will continue to be used for own.

Definition of A

A denotes any humanly feasible activity irrespective of the system in which it may take place. In other words, an A is not considered system-bound. Upon closer examination, we see that ADL and A do not fully coincide with own and alien, respectively. As mentioned above, own and alien are aspects of ADL. That is to say, they denote the distinction between usual and unusual activities. This distinction is conditional on the point of view of the observer; it does not result from an intrinsically different structure. ADL and A, on the other hand, denote a structural difference, namely whether or not something is system-bound, or to be more precise, whether or not the fact that it is system-bound is acknowledged. The fundamental distinction is thus between DL and A.

For most practical purposes, however, own may be equated with ADL (specific, system-bound) and alien with A (general, not system-bound). Moreover, both ADL and A denote concrete activities which are, or may be carried out by someone in some place at some time. Note that A does not signify an anomaly. In other words, the term as such is used to denote facts, it is not a moral valuation. To conclude, we draw attention to the fact that a logical consequence of the above definition of A, is that a so-called *ADL list* does not make much sense. Professionals should either use general A-lists (which are no more than mere checklists), or specified ADL inventories. Such inventories should be drawn up separately for men and women, adults and children, different professions, social classes, cultures or even individuals. However, under *normal* home circumstances, the soup need not be eaten as hot as it is served. In this light, it is worth repeating that the meaning of the terms ADL and A depend on the point of view of the observer: are we looking through the eyes of the performer or the onlooker, and who is the observer?

NOTES

1 IEEIR: International Exchange of Experts and Information in Rehabilitation.
2 Although the World Health Organization is now trying to introduce the sequence impairment – activities – participation instead of impairment – disability – handicap, impairment is still the building stone. This classification was and is intended to be used in a primarily medical context. I will call this the impairment-bound model.
3 See annex for a discussion on the concept of daily living (DL-concept).

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ISSUES OF DISABILITY ASSESSMENT IN WAR ZONES

William Boyce, Seddiq Weera

INTRODUCTION

Armed conflict and civil strife are widespread, affecting over 40 countries world wide in the past decade, according to the International Committee of the Red Cross. The majority of these conflicts are in poorer countries, and the principal victims are from poor families: those who cannot flee, and are therefore at greater risk of death and injury, and are less able to access rehabilitation services (Rehabilitation International/UNICEF 1991). In 1990, it was estimated that 22 million people had died in 150 armed conflicts since the end of World War II (UNICEF 1986). UNICEF also notes that for every child killed by war three more are seriously or permanently disabled, resulting in 4 million children physically disabled and 10 million psychologically traumatized by war during the 1980's alone (UNICEF 1991). Evidence from Afghanistan showed that incidence of disability nearly doubled among children living in zones of armed conflict (UNICEF 1990). Despite the great numbers and drastic situation, little data is available regarding the extent of rehabilitation needs. Reasons cited for this include the lack of time and energy for information collection during the chaos of war, barriers imposed upon personnel which forbid travel to remote locations where civilians are under attack, and the low priority placed upon concerns of disabled individuals, especially women and children (Rehabilitation International/UNICEF 1991). In ongoing war, epidemiologists face the special problems of continuous change where long term planning is virtually impossible, of military sensitivities impeding data collection, and of necessary compromise with respect to scientific rigour (Armenian 1989). At its worst, epidemiologists face manipulation of their data for military purposes.

The purpose of this paper is to discuss issues related to assessment of motor disablement in war torn countries and areas of armed conflict.

Initially, we discuss definitions of disablement based on differing socio-political perspectives, their influence on the development of measurement instruments, and the resulting implications for development of rehabilitation services. Secondly, we present the problems of disablement in war and the purpose of measurement at this time. Finally, we introduce some new concepts for development of disablement measures which have particular applicability in war zones, with the inherent need to maximize the efficient use of scarce resources.

DEFINITIONS AND PERSPECTIVES IN DISABLEMENT MEASUREMENT

Although there is considerable controversy over the appropriate meaning of disablement (Fougeyrollas 1992), the World Health Organization definitions provide a convenient starting point (WHO 1980). An impairment is a disturbance within an organ system and is defined as "loss or abnormality of psychological, physiological and anatomical structure or function". In contrast, a disability is "any restriction or lack of ability (resulting from an impairment) to perform an activity in a manner or within the range considered normal for a human being". Disabilities may be hidden or overt, temporary or permanent, and progressive or static. Finally, handicap is "a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on sex, social and cultural factors for that individual)". Since social roles are perceived and influenced by society, treatment of handicap requires social action in a broad sense (Chapireau 1992). Handicap is also influenced by environmental factors and by individuals' life habits, or psychological responses to the impairment or disability, particularly in response to the expectations of others (Bickenbach 1993; Fougeyrollas 1992). These definitional distinctions are important in disablement measurement and in the formulation of effective programme plans since they relate to prevailing socio-political attitudes towards persons with disabilities. It is also our contention that how disablement measures are constructed, applied, and interpreted can have major consequences. Historically, measurement of disablement has corresponded to prevailing conceptual developments in the disability field. (Kidd/Yoshida 1995) (Table 1)

Table 1: Traditional Disablement Measurement

Disability Perspective	Biomedical	Economic	Socio-Environmental
Primary Problem Location	Impairment Level	Disability Level	Handicap Level
Intervention	Clinical	Behavioural	Community
Action Orientation	Usual Plan →	Of Action & →	Resources →

Traditionally, disablement was defined from a biomedical perspective which emphasized the diagnosis, and causes, of impairment and which led to interventions such as medical and surgical services which dealt with the resulting physical problems. Measurement from this perspective focused on correctly identifying the biomedical problem and its causes in order to determine appropriate actions by clinicians and to allow prognosis of a return to normalcy. When used by itself, however, the biomedical perspective led to a charity model ("Nothing else can be done ... ") when these interventions were not successful in alleviating all of the person's problems. Disablement has also been defined from an economic perspective which emphasized the cost of disability to society and to the disabled person's sense of self worth. Measurement from the economic perspective has focused on accurately identifying a person's abilities and problems in order to assess eligibility for public services and to assess personal progress. This approach emphasized personal adaptation and technology solutions, and led to victim blaming ("It's your fault, you are not trying hard enough") when these interventions were not successful in alleviating other problems. Currently, disablement has been defined from a socio-environmental perspective which emphasizes the influence of physical, economic, social, and attitudinal constraints to participation of persons with disabilities in society. This approach emphasizes the interaction between handicaps and environmental problems, which leads to interventions directed at community barriers to integration. Measurement from the socio-environmental perspective focuses on identifying community-level social and environmental barriers, with the assumption that they potentially affect all persons with disabilities. If used by itself, however, this perspective can lead to untenable social change programmes which either are not affordable, fail to recognize cultural differences, or do not benefit those persons with more severe problems.

In the rare situations in which these diverse perspectives have been combined to produce more holistic measures, they invariably have a bias towards the biomedical and economic perspectives. Instruments usually begin with the collection of information related to the person's individual demographic, diagnostic, and impairment characteristics. The instruments then assess limitations in physical functions and disabilities. Finally, the instrument may assess the person's handicaps, or ability to function in the community, but usually without focusing on environmental barriers to social participation. This bias in the sequence of information collection is usually followed in the analysis as well, so that interventions based on the biomedical and economic perspectives, such as clinical treatment, adaptation, and technology, are prescribed first. Interventions based on the socio-environmental perspective are addressed only later, if at all. Limited resources are often channelled principally into medical and rehabilitation programmes with little remaining for community and environmental interventions. Measurement with this traditional approach often results in large amounts of unusable data about the person's impairments and disabilities which cannot be feasibly translated into effective programme recommendations, since there are also significant socio-environmental barriers to the achievement of the individual's goals. Additionally, especially for those with chronic problems, impairments and disabilities may be quite fixed, with few clinical or adaptive interventions being useful. This predicament results in little change for the individual from the assessment process. Persons with disabilities have argued that the consequences of these measurement practices have been detrimental to them. They are often required to go through extensive assessment, clinical programmes, and behavioural procedures designed to address impairment and disability problems which they feel do not address their major concerns in living in communities. Some slow progress has been made through political advocacy to redress these situations. However, the situation of disablement measurement in areas of armed conflict does not appear to have changed, probably due to the general disenfranchisement of civilians in war.

WAR AND DISABLEMENT PROBLEMS

During armed conflicts, motor disabilities in communities are more extensive, and include a greater variety of problems in comparison to stable times. Impairments, disabilities, and handicaps also vary during different stages of a conflict – from instability to open battle to reconstruction.

1. Impairments incurred during conflict may include peripheral nerve injuries caused by bullet and/or shrapnel wounds; hand, foot, facial injuries, and blindness caused by explosions or torture; and head, chest, and orthopaedic injuries caused by explosions or collapse of buildings. After hostilities cease, civilians may continue to suffer impairments, such as amputations and blindness caused by landmines. These impairment problems result in needs for specific clinical programmes such as surgery and prosthetics.
2. Disabilities which can occur during conflict may initially include being weak, unable to see, and unable to protect oneself during armed attack. At later stages, being unable to rapidly respond to curfew, and being unable to look after basic hygiene and self care may become problems. These problems result in needs for specific rehabilitation programmes such as muscle strengthening, mobility training, vocational retraining, and provision of adaptive devices.
3. Handicaps which are experienced during times of active conflict often include being unable to safely earn a living. In post-conflict situations, one may also be stigmatized as a disabled veteran. These problems result in needs for specific community based programmes such as public education, income generation projects, accessibility modifications, and peer support programmes.

THE PURPOSE OF DISABLEMENT MEASUREMENT IN WAR ZONES

The objectives of health and disability measurement in less developed, war torn countries differ from those in developed and politically stable countries. For example, measurements of disability in the latter are generally needed for diverse purposes such as determining compensation, predicting prognosis, planning placement, estimating care requirements, choosing types of specific care, and indicating changes in functional status (Feinstein et al. 1986). Many of these purposes are related to the biomedical and economic perspectives previously discussed. Needless to say, in developing countries and war-torn countries in particular, data collection for the sake of pure research or esoteric planning is not an efficient use of limited resources. In most war-affected and developing countries there are no census data available, nor do credible health information systems exist. The primary purpose of measuring disablement in war and conflict zones should be to plan immediate institutional and Community Based Rehabilitation (CBR) programmes which can alleviate human suffering and the disruption of routine activities caused by physical injuries.

CBR is:

> a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. (ILO/UNESCO/WHO 1994)

Community based programmes will not be effective in war zones unless conflict related issues are considered in the planning process. How can we be assured of measuring the right aspect of disablement? Instruments for measurement of motor problems in war zones should be carefully constructed, applied, and interpreted to give optimum information for realistic decision making. To do this, we need to re-visit the basic concepts of disablement from a new perspective.

RECONCEPTUALIZING THE MEASUREMENT OF DISABLEMENT

Reliability, validity, and conceptual clarity have been identified as major problems with most functional capacity measures. McDowell and Newell (1987) have reported that most functional scales are not built on any conceptual approach to disability, and that scant attention has been paid to formal methods for standardization. There are several conceptual clarifications which are needed in the development of disablement measures. Traditionally, impairment scales have been used to address physical capacities, such as strength, balance, sensory abilities, and range of motion. Similarly, disability scales have been used to address gross physical movement, self care, and technology needs, whereas handicap measures have addressed the fulfillment of social roles, working abilities, and household activities. Thus, measurement of disablement concepts generally follow the WHO definitions provided earlier. However, these measures are often applied indiscriminately, are used to collect large amounts of information which is wasted, and do not incorporate an adequate assessment of the environmental context, which is of major importance in both developing countries and areas of war.

The concept of Activities of Daily Living (ADL) has also been utilized in disablement measurement. ADL includes a person's capacity for managing basic hygiene and self care (eating, drinking, washing, toileting, dressing and undressing), and mobility. An associated concept, Instrumental Activities of Daily Living (IADL), includes activities typically experienced in living in the community such as shopping, cooking, managing money, work, school, and recreational activities. Thus, IADL concepts extend the disability theme of ADL to include some elements of handicap, but again without considering environmental and attitudinal barriers which are inherent in handicap. A recent conceptualization of ADL has incorporated some culturally influenced aspects of disablement in community settings (Vreede 1994). Vreede (1993) has also suggested three components of ADL which correspond to impairment, disability, and handicap problems. Each of these components has different implications for planning CBR programmes in developing countries. *Operations for Daily Living (ODL)* are physical or mental exertions, such as using one's legs to walk. *Activities for Daily Living (ADL)* are intentional activities, such as walking to the market. *Ideas for Daily Living (IDL)*are concrete daily roles, such as selling goods in a local market. For example, a women market vendor with a leg amputation caused by a landmine could have a problem in not being able to earn a living (IDL) if, as a stigmatized disabled person, she is not allowed to secure a strategic spot in the market. The woman may not have any impairment or disability which needs to be addressed. One would not want to waste time or resources investigating them. The woman's problem could be alleviated if, through public education and advocacy, the other vendors agreed to reserve a spot for her (a community intervention). The woman could also have a problem in walking quickly to the market (ADL). Again, the woman may not have any impairment which needs to be addressed. However, this problem could be alleviated if she performed strengthening exercises (a behavioural intervention) or used a crutch (a technological intervention). Finally, the woman could have a problem with pain when using her below knee prosthesis (ODL). This problem could be alleviated by re-fitting her appliance (a clinical intervention). Thus, each of these problems in activities of daily living (IDL, ADL, ODL) has different causes, different solutions, and requires different programme plans from various community agencies. In this and many similar situations, unless an appropriate methodology is used to assess the person's needs, there is the potential for considerable waste of time and resources, with a real risk that the most important problem will not be addressed.

CONCEPTUAL FRAMEWORK FOR A WAR ZONE MOTOR DISABILITY MEASURE

In the context of war zones, wherein people suffer acute violent injuries, disablement measures must obviously cover a broad range of impairment, disability, and handicap problems. However, these problems of disablement should be considered through an assessment which establishes the priority needs and solutions from the community's perspective. Given that there are no disablement instruments which have been developed for use in areas undergoing armed conflict, there is a need to develop such instruments and test them for validity and reliability in the field. Such an instrument must be able to distinguish between individuals with impairments, disabilities, and handicaps and also between those without them. The methodology must be culturally specific, be sensitive to stages of conflict, have a sharp focus on community and individual priorities, and be able to efficiently collect and analyze data to assist in planning programmes. Primary sources for an instrument which meets these criteria include the works of Vreede (1993), Beach, Boyce et al. (1995), Berry and Dalal (1996), Weera (1996). We suggest that, for community programme planning purposes, a needs based methodology be developed. This approach recognizes the priority of the target group in defining their own needs and programmes. (See Table 2).

Table 2: Community Based Disablement Measurement

Needs Based Measurement	Environment →	Limitations →	Capacities
Problem Location	Ideas of Daily Living	Activities of Daily Living	Operations of Daily Living
Intervention	Community	Behavioural	Clinical
Action Orientation	Action	and Resources*	

* Financial, personnel, and logistical resources are often spent on biomedical and clinical services rather than on socio-environmental solutions to disablement problems.

In considering the context of physical disability in war zones, it is desirable that socio-environmental information be assessed first. Without knowing the cultural context, even in a peaceful area, one cannot effectively plan community programmes. Similarly, one needs to know the conflict situation in war zones, both for planning appropriate interventions as well as for assessing programme logistics and feasibility. The community based disablement assessment begins with key informants being asked for a brief description of the geographic context, current and previous conflict activities, and the presence and removal of landmines, including public education efforts. Information on community development activities, major competing health, economic, and social concerns, and locally available community resources are also gathered. Finally, cultural norms for disability, and the key informants' perceived needs regarding disablement, are collected. A household questionnaire includes socio-demographic information gathered from the family head, as well as a specific disability screening section. If a person with a disablement is present in the household, further questions are asked in a manner which respects the conceptual issues discussed previously.

1. Roles and Expectations:
Key Questions
What job or role do you have in the community?
What is your family role?
What are your self care activities?
What leisure activities do you enjoy?
These questions provide important information regarding personal abilities and ambitions, as well as information about the local cultural context of disability.

2. IDL Problems – Environment:
Handicaps, or socio-environmental (physical, psychological, and social) barriers, are then assessed and IDL problems are identified.
Key Question
What in your environment prevents your usual role?
Questions are addressed appropriately for children (play, schooling) and adults (employment, family status, recreational activities, social support). Recommendations for developing programmes at the community level of intervention are the priority for these problems.

3. ADL Problems – Limitations:
Next, disabilities, or physical limitations, are assessed and ADL problems are identified in the areas of hygiene, self care, posture, and mobility.
Key Question
What functional limitation does your body have?
Recommendations for developing training programmes for individual behavioural change as well as adaptive equipment programmes are the priority.

4. ODL Problems – Capacities:

Finally, impairments, diagnosis, and physical capacities are assessed and ODL problems are identified. Congenital and acquired sources of disablement are specified, including the source of conflict-related injuries (landmines, explosions, shrapnel, bullets, torture). Physical problems of pain, range of motion, strength, deformities, and medical conditions are assessed.

Key Question

What is the impairment or cause of this limitation?

Recommendations for developing programmes for clinical services are a priority in this situation. Other programmes for IDL (handicap) and ADL (disability) may also be needed in conjunction with clinical services. The strength of this approach is that priorities from the community members' perspectives are addressed first.

SUMMARY

This paper reviews the conceptual, measurement, and practical issues faced by planners concerned with providing rehabilitation programmes in areas of conflict. A new measurement approach which builds on the emerging recognition of a socio-environmental perspective in disablement is presented as a useful methodology for community needs assessment of motor problems in war zones. An instrument based on these principles is currently being field tested in CBR programmes in Afghanistan and Central America.

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THE PARTICIPATORY RAPID APPRAISAL METHOD OF RESEARCH ON CULTURAL REPRESENTATIONS OF DISABILITY IN JORDAN

Majid Turmusani

CURRENT CRITIQUE OF DISABILITY RESEARCH

Traditional research has played a part in the oppression of people with impairments by conceptualizing disability as individual tragedy to be pitied rather than as embodied in social relationships (Rioux 1994). As a result, it is argued that the assumptions underlying some methodological approaches have been consistent with other negative and exclusive behaviors and attitudes relating to disabled people within wider society (Stone/Priestley 1996; Rioux/Bach 1994). For example, survey methods have characteristically treated disabled people in Jordan, as elsewhere, as passive subjects of the research enterprise, thus contributing to their marginalization. The survey of 1991 on the situation of disabled people in Jordan conducted by the Department of Statistics and Surveys (DSS) is an example of past research which is regarded as *disabling* (DSS 1991). The emphasis of this survey was on assessing the needs of families rather than the disabled individual. As a result, this research did not substantially contribute to a comprehensive identification of the needs of disabled people, nor therefore to meeting such needs as might be defined by disabled people themselves.

Although disabled people have frequently been treated as passive research subjects (Abberley 1987), in recent years they have increasingly rejected the individualistic tragedy view that has been presented by traditional research and are calling for a more democratic paradigm in researching their needs. Although some previous research which has utilized an emancipatory framework could occasionally be said to have transformative potential, it is clearly not emancipatory in terms of the two primary principles of empowerment and reciprocity which are essential for any research with transformative potential (Zarb 1992). Disabled people have advocated an *emancipatory paradigm* whereby they are in greater control of the research process and its production

(Oliver/Barnes 1997). This new paradigm is consistent with a theoretical approach which looks at disability as socially created and a culturally produced form of oppression, or what is known as the social model (Oliver 1990/1996; Abberley 1987). The key feature of this approach is a re-definition of the social relations of research production (Stone/Priestley 1996; Priestley 1997) and it is the practical relevance of interpretive research to the lives of research participants in removing the disabling barriers which is the most important theme of the emancipatory paradigm (Oliver 1992).

The emancipatory research is an approach which emphasizes greater control of disabled people over the agenda, participation in the research and gaining strength in the process. Although this research recognizes that most research serves the powerful, it challenges inequality by supporting people in the creation of their own knowledge and strengthening their abilities and resources. Emancipatory research – which advocates democratization of the research process and initiative coming from research beneficiaries, so far as possible – bears similarities to a wider category of participatory methodologies. Oliver (1992) advocates an emancipatory approach which minimizes the role of outsider expertise and maximizes the full role of disabled people in the production and ownership of the research. He argues that disability research should not be a technique carried out by expert able bodied people, but should constitute part of disabled people's struggle to challenge the daily life experience of oppression. This suggests that a researcher's expertise should be put at the disposal of disabled people to enable them to become empowered. However, Oliver contends that research can never directly empower people, since empowerment is something that disabled people must claim for themselves. Research, he suggests, can only facilitate this process when people have come to address their own disempowerment irrespective of those individuals who have in some way benefited from that disempowerment in some way in the past. In conclusion, Morris (1992) sets out four elements which she regards as fundamental for an emancipatory approach:

1. The research should play a role in personal liberation.
2. The personal experience of disability should be revealed clearly.
3. Non-disabled researchers must present themselves as allies and resources.
4. Disability research and disability politics are of general relevance to all social groups.

In practice, it has proven extremely difficult to implement an emancipatory approach. Disabled people are frequently denied any opportunity to take part in research, and researchers are often not willing to make their research accessible to them (Barnes/Mercer 1997). This is especially true in the South where disabled people until recently have been denied any opportunity to influence the agenda of the research process, which has typically involved the use of survey methods which in themselves have proved to be inadequate in researching disabled people's needs. This may be largely because the dominance of the medical model of disability, which in some way fuels the more general belief that disabled people are not able to participate in the economy because of their personal inability. Given the problems associated with implementing emancipatory research, especially in the South, and in order to remedy past inadequacies of traditional research, it is important to use an approach based on an alternative participatory research model for studying disabled people's economic needs and rights in which the role of researcher is changed as far as possible from that of controller to facilitator who puts professional research skills at the disposal of disabled people.

Disability Research in the Developing Countries: the Prominence of Participatory Rapid Appraisal Method

The analysis of the literature on disability shows a tendency to support the use of a participatory approach when researching disabled people in developing countries (Helander 1993). Participatory research is an approach which has been evolving in recent years, particularly in developing countries, and has been the subject of different interpretations. French (1994) pointed out that the main aim of participatory research is to involve people in an active way at every stage of the research process including topic selection, determination of methodology, and evaluation. It also aims to educate decision makers, especially those involved in some part of the research process. That is, they can learn about the local culture and the specific circumstances of the community which helps in a better understanding of the needs of these communities when making policy decisions. In this sense, this method is considered to be a democratic tool which can accelerate social change. This is because it allows a greater degree of participation by the target group along with policy makers in controlling research production.

One participatory methodology particularly common in developing countries is PRA. Although not used extensively in disability research, it has been suggested as a method which has a particular relevance to disabled people in Jordan. Its advocates regard it both as a means of eliciting useful and reliable data and ensuring the involvement of beneficiaries. Some of those advocates see it as having similar potential for democratizing the relationship between researcher and researched as emancipatory research. While not a method which has therefore been used extensively in disability research, it has undoubted potential in this regard, especially in settings in developing countries. PRA is a specific form of rural rapid appraisal that was introduced for of variety of reasons – largely the limitations of time and funding which have been associated with conventional approaches such as traditional surveys. These approaches perpetuate the problem of misunderstanding the needs of the poor and have tended to make inappropriate provision for them (Thies 1991). While proponents of PRA argue that it offers improvement over some conventional techniques such as surveys, others contend that it complements surveys. Perhaps what matters here is the fact that PRA serves to improve the quality of data obtained, and this can be used especially for further decisions (Turmusani 1993). As a method of needs assessment, PRA is based on informality and a high level of participation of the target group (Thies 1991; Chambers 1983; Chambers 1994a; Bunch 1982). It is characterized as a comprehensive, practical, and quick means, as we will see shortly, to identify, analyze and evaluate their own situations and generate solutions to certain problems.

PRA provides opportunities to learn from and with local community members in order to understand the complexities of a certain topic in a broader manner with regard to the topic rather than focusing on gathering very accurate statistics on a certain list of variables related to the topic. It can be argued that PRA may be distinguished from other methods in terms of the cost associated with it, the level of transfer of power to disabled people within the research process, and speed of application in the field. As in other methodologies, rapid appraisal methods including PRA use well designed tools for data gathering and analysis appropriate to the task at hand, such as direct observation, semi-structured interviews, ranking, as well as gathering data from different sources, which helps to achieve more accuracy (Niio Ong 1991; Murray 1994; Chambers 1983; Bunch 1982; Theis 1991).

They cover a variety of methods and techniques, but all these tend to have the following characteristics in common:

- They permit greater speed compared with conventional methods of analysis.
- They involve working in the field, and emphasize learning directly from those in the locality.

- They combine a multidisciplinary approach or what is called *triangulation*[1] with flexibility and innovation.
- They place emphasis on producing a timely insight, hypothesis or *best bets* rather than final results or fixed recommendations (Pratt/Loizos 1992; Chambers 1994b and Theis 1991).

However, PRA is different from other participatory methods such as participatory rural appraisal mainly in shifting power from outsiders to the locals or at least sharing it by allowing a greater level of participation of the target group in the whole process of research and decision making (Pratt/Loizos 1992; Thies 1991). PRA is also described a creative method in the sense that it allows greater opportunity for using, amending, or adding a certain tool according to the requirement of the research at any stage of the field work. Also it gives the opportunity for continuous revision of the data gathered and quick decisions for further gathering. Nevertheless, research of this kind has some weaknesses and limitations: The first is a weakness related to community co-operation and participation. The PRA method might perpetuate a dependency attitude within the target group who then expect an outsider to do most of the research work. The second weakness concerns the skills and objectivity of researchers. The third weakness is related to target group representation such as when the target group can really participate in all phases of the research, does it consider representatives of gender, area, background, etc. The major limitation of this participatory research is the limited level of disabled people's participation in controlling the research process. In practice, research on disability issues in the academic field tends to involve co-emancipatory research or collaborative research. True participatory methods focus on allowing disabled people to be fully involved in the research process and in decision making as well (as part of their emancipation).

TO WHAT EXTENT HAS THE PRA-METHOD TRANSFERRED POWER TO DISABLED PEOPLE?

Evidence shows that discrimination is the key problem that pervades the lives of disabled people in Jordan, compounding the consequences of their disability and pushing them to the margins. Research findings on the economic needs of disabled people in Jordan reveal the severe disadvantages experienced by disabled people in the areas of employment, welfare benefits, access, and mobility. Although many disabled people viewed the satisfaction of their identified needs as a matter of charity, a substantial number of them rejected this charitable attitude and called for access to the same rights and opportunities as other members of society. Awareness is the solution and information is the most likely approach to overcome the basic ignorance that creates discrimination. It can be concluded that accurate information on the condition of disabled people could be obtained from research that allows the involvement of disabled people themselves in the process and the control of its production, as this may constitute a step in their emancipation (Turmusani 1998).

This section explores how far the involvement of disabled people in the research process via PRA has helped to translate their individual experience in life into political actions. Prior to that, however, a note on the empirical research will be provided. The empirical research on which this paper is based investigates the economic position of disabled people in Jordan and assesses how disabled people themselves evaluate their economic needs and priorities, with secondary emphasis on the way in which existing legislation is addressing this issue. The main concern underlying this research is its contribution to a change in attitudes towards disability issues and particularly to the economic participation of disabled people being viewed at the level of society instead of that of the individual. This research, which was conducted during 1996–1997, concerned a target group of 181 disabled people who were interviewed within the course of this research to give information regarding their needs and priorities, including their needs for a positive change in attitudes towards them. This target group included males and females from both rural and urban settings, all of whom had sensory impairments (blind, deaf) or were physically impaired and were attending vocational, sheltered, and self employment programs in the Middle Region of Jordan (Turmusani 1999). Throughout the process of research the awareness of those who took part in the discussion of their own condition as individuals is moved to that of social structures that restrict their development and consequently perpetuate their passivity and inhibit their emancipation. Although the medical understanding of disability has dominated and influenced those who made up the sample in this research, the collective response of those who made up the focus group sessions has revealed a political perspective in the way they viewed their needs and rights. It was observed that there was a personal progression in thought for those individuals who took part in the focus group. They sometimes got involved in the discussion and moved their views from the (individual) personal to the societal and from charity to a perspective of rights.

Consequently, this (the involvement of disabled people in the research process) would stimulate their emancipation and help their empowerment. Empowerment here means allowing and enabling disabled people to take control. It is a process whereby disabled people are left to explore the extent of their potential and overcome their limitations dictated by the negative attitudes of society. Therefore, it would seem appropriate for a participatory policy agenda targeting disability issues to consider the environment as the focal point of action.

CONCLUSION

This paper attempted to highlight the extent to which the PRA method can play a role in facilitating the emancipation of disabled people. The idea is to allow disabled people to be in full control over their lives, in line with the social perspective on disability. The paper shows that there are number of limitations associated with PRA when implemented with disabled people, which may limit the level of transfer of power to them. Thus, there is a need for caution when using participatory research, especially if it involves academic work. The paper concludes by reaffirming the need to distinguish the role of researcher from that of controller to facilitators by putting their expertise at the disposal of disabled people. Disabled people should not only be regarded as a partners in the research process but also as owners of research production. In brief, this paper explored the political and methodological issues involved in doing disability research and how this can contribute to the development of a more emancipatory approach in future disability research in Jordan.

NOTES

1 Triangulation means multidisciplinary team, data from different sources and places and using different tools for data gathering.

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USING HISTORICAL ANTHROPOLOGY TO *THINK* DISABILITY

Henri Jacques Stiker

It has to be explained at the outset that in French, we are obliged to use the word *handicap* to cover what is understood by the term *disability* in current Anglo-Saxon usage. The word *handicap* has been adopted and adapted in French as the *least bad* generic term. Protest as one might against this, a language is nevertheless made by language users, the people who speak it. It is not worth agonising over it further.

INVITATION TO THINK

In France today, disability is thought of in relation to the issue of what is known as *exclusion*, that is, in relation to the form which has been taken by the social question. In *La nouvelle question sociale*, one of the best analysts of French society, Pierre Rosanvallon, treats the problem of disability as a sort of exception against which others can be set off. In the context of his analysis of the impasse in the social question and possible ways out, one major danger is apparent to the author: that of paying the wages of exclusion, as he puts it so well. That is to say, our societies would be rich enough to compensate those whom they can no longer fit or integrate into the economic sphere. From this perspective *disability* is a category which it is not advisable to move from the medical domain into the social. One can allow that *deficient* people are dependent on solidarity, as seen by the welfare state, but since this would extend the category, it would mean perversely institutionalising the separation between the economic and the social, *putting the society of compensation on a par with the society of exclusion*.

> The category of social disability was invented in the 80s, just as the category of unemployment was invented at the end of the 19th century – in order to deal with the population which could no longer be normally fitted into society. In this case, the citizen lost out morally where the receiver of unemployment benefit gained financially: a form of solidarity is practised at the price of being sidelined by society. (Rosanvallon 1995: 118ff., our translation)

With this introduction I would like to emphasise two points: firstly, in each country or cultural area, disability is conceived of differently; and secondly, it is conceived of in the light of the prevailing situation in that country. I believe accordingly that disability may be, and indeed must be, confronted and examined theoretically, historically and sociologically. A *permanent dimension* of the societies must be taken into consideration here. Why have power, sexuality, religion, poverty, gender, etc. been thought through, but not infirmity (I use this word since it is the least laden with preconceived meanings)? It is neither a negligible subject, nor merely an appendix to the social question. It is we who obliterate it, to the point of thinking it *is* thus – just as was done, for a long time, with women or mental illness. I will spare you an account here of the very detailed nature of ideas on disability as demonstrated by the French example. It would be of little interest to recall a history stretching from the *blind workers* of the French Revolution and the *industrial accident victims* of the end of the 19th century, then the *war wounded*, mentioning in passing the notion of *maladjustment* in the context of the ideology of World War II, to finally arrive at the construction of the notion of disability (or *handicap* in French[1]), confronting the notions of marginality, then of exclusion. Not to forget P. Wood's proposal adopted by the WHO, which has had a significant career in France!

FROM STIGMA TO OPPRESSION, OR THE SOCIOLOGY OF POLITICAL ANALYSIS

In the Wake of the Chicago School

Most sociology courses now mention the work of Erving Goffman, and in particular his book *Stigma. Notes on the management of spoiled identity*, and also Howard Becker's work, with its concept of deviance, which is likewise a product of the interactionist and microsociological Chicago School. These works have been used to saturation point to consider the issue of disability and disabled people. Not only did this lead to a failure to find any compromise with social intervention and to establish any overall plan, but the question of disability was linked to other socio-psychological phenomena, and disabled people to other groups. The fact of a mark on the body to indicate disfavour, disgrace, deepest disrepute, as had been made on slaves, outlaws, prostitutes, and as was made on the Jews, constituted a way of seeing how an infirmity (or monstrosity or deformity, it's all the same), gave way to a virtual social identity displacing completely the real social identity, just as happens when race or character are stigmatised. There is daily confirmation just how true it is that a deficient person becomes

> an individual who might have been received easily in ordinary social intercourse (but who) possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. (Goffman 1964: 5)

The phenomena of the stereotype, or the amalgamation of ascribed traits, are most evident when it comes to deficient people, and in Goffman's thinking appear as established, daily fact. The same goes for his insistence on the reference to an established social norm. After having described the norms applied to the American male of the 50s, he writes:

> Any male who fails to qualify in any of these ways is likely to view himself – during moments at least – as unworthy, incomplete, and inferior; at times he is likely to pass and at times he is likely to find himself being apologetic or aggressive concerning known-about aspects of himself he knows are probably seen as undesirable. The general identity-values of a society may be fully entrenched nowhere, and yet they can cast some kind of shadow on the encounters encountered everywhere in daily living. (ibid.: 128)

In such texts we can read the attitudes currently encountered amongst the disabled and those around them. The purpose here is not to give an account of Goffman's thinking, but rather to show how opportune his appearance on the scene was, insofar as it proved a powerful aid to developing studies on the social representation of disability and disabled people.[2]

On the level of content, I am not certain whether any very new stage has been reached with regard to Goffman, studies on social representations having shown in detail the general underrating of people who are marked either in body or mind, the hierarchies between deficiencies and the historicity of representations (Ravaud/Ville 1994), without actually questioning either the interactionist approach or the notion of stigma as applied to disabled people. For in this sociology of interrelations, disability *qua* infirmity is completely circumscribed – unusually for something otherwise always located on the frontier to the phantasmatic, in search of identity through the mirror, through social practices, which will contain, situate or relieve it. Disability cannot be conceived of outside of the sphere of the psyche, because it returns again and again to the image of the self, both that of the disabled person and of the onlooker. The gaze of others is a complex of preconstructed gazes, of introjected gazes of other people, of the own introjected gazes. In fact, I wonder whether psychoanalysis, which has only recently begun to take a major interest in disabled people, would indeed have done so without the mediation of psychosociology. This is however a secondary debate; what is certain is that the Chicago School was in a good position, sociologically speaking, to apprehend and think about disability.

If one furthermore takes into account studies of outsiders, about whom the work of Norbert Elias[3] has shown us the real nature, independent of economic or social conditions, then we have the means to approach the disabled situation as an issue in its own right. At the same time, it is possible to go beyond Goffman and Becker. To set down the difference between the *established* and the *outsiders*, there is no need of marked or stigmatising physical traits, nor of fundamental economic and cultural differences. The difference can be constructed out of nothing: it suffices that an established group perceives another as intrusive, bizarre, nonconformist, menacing to identity, etc., and that the former group tells itself this persuasively.[4] As Michel Wierviorka says in the foreword to Elias' book, "the situation is astonishing, since it exposes racism without race, and exclusion without economic division" (Elias/Scotson 1997: 13, our translation). I should add that the rejection of disability is often exposed without there being any particular monstrosity and independent of a particular socio-economic context. The disabled are perceived as outsiders because they offend, because they threaten the image we have of our tidy little identities as people in possession of their faculties, as useful, profit-bringing workers, and various other things of this nature.

> The power of Elias lies in his capacity to produce coherent argumentation, in which he articulates that which has before generally been separated or simply juxtaposed, like so many distinct factors and registers. Thus the structure of the family appears, in this analysis, inseparable from that of the community which Winston Parva constitutes in its entirety ... from there one passes on to the associative life ... (ibid.: 20, our translation)

As in the case of Goffman, but undeniably in a much nicer way, this type of sociological analysis allows us to confront the question of disablity where it is actually situated: at the intersection of the individual image of oneself and the collective image of the group, the intersection of the paths between phantasm and cultural representation.

If any, this would be the moment to recall Marcel Mauss – not only his concept of the social fact as such, which makes it possible to link the individual and the social, but his idea of a relationship of translation between the individual and the social. As Bruno Karsenti wrote, it is "the unique expression, elaborated on the individual level itself, of a sociological structure", and this is possible thanks to the "status of the symbol" (Karsenti 1994: 85, our translation).

> That which allows the notion of the symbol, is, in short, the bypassing of the confrontation with realities which have been ignominiously hypostatised by the social sciences: in this conception there is no longer either individual or society, but only a system of signs which, by mediating the relations which each has with each, constructs in one and the same movement the socialisation of individuals and their unification in a group. (ibid.: 87, our translation)

There is a symbolic commensurability between the individual and the collective, because there is a symbolic function, a flexible, versatile whole which ramifies into one another's always different and often distant spheres. To me, psychoanalysis appears to constitute an area of convergence between the individual and the collective. Moreover, this is not, I believe, very far from Freud's conception in his *Massenpsychologie und Ich-Analyse* (1921), which I compare with Mauss' *Real and Practical Relations between Psychology and Sociology* of 1924. Freud pointed out that the individual's relations to his/her parents and siblings, beloved, teacher, doctor, etc. – i.e. the relations which had hitherto been the object of psychoanalysis – could also be considered social phenomena. Individual and social psychology, according to Freud, could thus not be separated.

Referring to totems and taboos, Mauss for his part writes,

> we believe that these ideas have the capacity for enormous development and persistence, and from the way they haunt the individual consciousness we understand better why they are believed when, practised by the group all together, they are verified by the the common obsession of the group. (Mauss 1979: 14)

For us, this contains a very valuable blueprint for the analysis of disability, constituting one of those "symbolic nodes ... privileged points in a symbolic network where the significations most valorised by the group are gathered and tied together"(Passeron 1992: 330, our translation). And Karsenti continues: "places from which the classical dichotomies of earlier sociology may rightly be dissolved. And in the forefront of these, the opposition between the individual and the collective" (op. cit.: 94, our translation). Disability and impairment are one of these nodal points where everything psychoanalysis has been able to discover is knotted together (on the part of parents of disabled children, there is trauma, stupefication, guilt, murderous impulses which turn into overprotection, blame directed at the previous generation or spouse, the impossibility of mourning, quest for personal or sexual identity, etc.,[5] together with whatever sociologists or psychosociologists have brought forth (the image of the *mauvais objet*, the stigmas of danger, contagion or ugliness; portrayals as slow, absent, irritating, boring or powerless, as an example of courage or heroic willpower, overstepping the limit, being called to order by modesty, etc).

Disability is quite definitely a different thing from a *social problem*, just as disabled people are quite definitely not some category of deficient beings. But in order to see this, however, one has to break away from the vocabulary of disability, and go back to a time before it was introduced, if only so as to be better able to decipher what lies behind this perception. Because whichever way the problem is turned, and whatever the fuzziness of the criteria, however ideological, envisaged by the *medical model* or the *social model* today, there is always a hard core consisting of an impairment of functions, of organs, of bodily or mental structures (taking these two adjectives to apply to the human individual in total). To put it otherwise and more simply, beneath the disability there is always the problem of *infirmity*, which triggers off something other than the simply socio-economic; this mobilises the symbolic, and the social and economic position of these *infirm* people can itself only be understood if the connection with this symbolism is made. This is what is not understood by those (to my mind somewhat uninspired) approaches which tend to *drown* the problem in other problems: poverty, precariousness or exclusion, in the contemporary sense of the terms. However, this assertion is by no means self-evident, even though it is, in my view, fundamental not only to establishing proper measures, but above all to preventing the emergence of a subtle new line of isolated and unilateral thought. One can see a succession – or sometimes the simultaneous *cohabitation* – of what could be termed *ideas of the whole*: the essentialist whole, the socioeconomic whole, the psychological whole, the organic whole, the genetic whole. Although these adjectives are not of the same kind, they nevertheless show the waves of intellectual fashion which are the inverse of Maussian thought.

From the British Side

To give it the due it deserves, I would like at this point to examine a school of thought established at universities in Great Britain, thanks to disabled researchers and teachers who publish a great deal, and also put out the journal *Disability and Society.* Their basic assertion is that disability can only be understood if all lines of access, even subtle ones disguised as *impairment* and thus inevitably medical and individualistic, are rejected and the issue is analysed in terms of the *social model.* But what is the *social model*? What they reject is clear enough: medical or psychological evaluations or discourses which claim to define the possibilities, the places, the roles, the stages to be gone through etc. as a function of the measurements and the diagnostics relating to the deficiency. More generally, they reject anything which, starting from the specific point of view of the deficiency, tries to circumscribe or locate them, and – more often – to inferiorise them. Just as black minorities or homosexual groups are regarded solely from the point of view of that which differentiates them from others, which entails forms of oppression, disabled people (who, by a sudden and curious turnabout in semantic usage, should only be spoken of in terms of *disability* or *disablement*, and not of being *handicapped* [the term used in French, translator]) must be considered oppressed. To think about disability one has to think about the social barriers and the reasons for these social barriers, in terms of their sociological and political determinants. And the best way to do this, here indeed it is an epistemological prerequisite, is to be disabled oneself. Every utterance, every piece of research which is not *from within* or *interior* or at any rate not emancipatory, has a basic flaw running through it, since it participates of necessity in an external discourse which, in oppression-producing Western society, belongs of necessity to the domain of the *medical model*; that is, it is essentialist, individualist, specifying, and constructed with the aim of avoiding participation and integration. The deeper motives of this situation, in which things are treated in terms of deficiency (something not escaped by the Chicago School – which nevertheless inspired them, at least initially – nor by Murphy, whom I will discuss below) are to be found in the socio-economic structures which dominate such representations. Here, neo-Marxism is in play. So as not to deny the interest of viewing things from the angle of imagination, nor from the properly anthropological one, the most rigorous adherents of this school of thought openly declare themselves materialists.[6] Nevertheless, the genealogy of the idea can be reconstituted without Marx or Gramsci, as Colin Barnes indicates.

Taking Parsons (1951: chapter X) as a starting-point, one can clearly show that disease and illness are constitutive in the same way as as social deviance is, since they withdraw the individual from her or his active role as a producer and economic agent, which presupposes good health. Medicine, then, has to cope with this social menace and thus becomes an indispensable cog in the smooth functioning of society, contributing to the maintenance of social stability. The doctor is the only one entitled to say who is sick and who is not. She or he exercises social control by channelling the potential deviance represented by the illness. Medicine is the servant of economic and social objectives, and of the community. What is true for sickness and disease is undoubtedly even more true for disability. Parsons, together with Goffman, Becker and Scott, made it possible for commentators in the 70s to put an ever greater stress on the importance of social factors in issues relating to disability.[7] An industrial, liberal society which stresses work and performance rejects all those unable to contribute to the healthy economy of the community. In 1976 the Union of the Physically Impaired Against Segregation (UPIAS) gave this definition of *disability*:

> disadvantage or restriction of activity due to contemporary social order which either does not or does not sufficiently take into account people with physical impairment and consequently excludes them from major social activities. (our translation)

The definition is a good deal more sociological than that of Wood/WHO, and endeavours to establish the economic origin of the barriers which constitute disability.

It would be desirable to discuss this briefly-evoked British line of thinking in much more detail than I have here, and to distinguish it from the American current of thought. The latter remains attached to a cultural analysis which maintains fairly close links with the surrounding culturalism. Indeed, in the United States, around the *Independent Living Movement,* the journal and the network *Disability Studies* – behind which Irving Zola (also known for his studies on pain) was the moving force right up to his death – the cultural analysis operated on two levels: representations of disability might depend on factors related to religion, language and tradition on the one hand; on the other, disabled people formed cultural groups with their own specific features, starting from life conditions, a story, etc. Just as the women's movement engendered *women's studies* in response to a demand for a *culture of femininity* which would only be completely comprehensible to women themselves, so it is with people with disabilities (this is the term which is used, quite simply, in the U.S.A., although the expression is challenged by the British writers I have mentioned, as it retains a specifying aspect). The case which undoubtedly gives the most weight to the privileged position on the other side of the Atlantic is that of the deaf. By this I mean people who are deaf from birth or at least those who – even though they may also be bilinguals and utilise various language media – form part of the community that has to use sign language. This community, which has been forbidden to use its own language for a century[8], can with some justification claim the status of a minority community. The argument goes as follows: we are speakers like any other speakers; we have a language; admittedly, a language of signs and not sound, but a complete language in its own right. By the same token, we also have a way of thinking, of situating ourselves, in short, a way of being-in-the-world. Our inferior status draws us together with communities of cultural minorities whose minority status or *foreignness* make them inferior in a dominant and dominating culture. From this point, it can clearly be seen how the notion of disability becomes more removed or a secondary trait – indeed is rejected completely. In this, the deaf community has adopted a good deal from the American culturalist interpretation with regard to blacks, women and Mexicans. It should not be forgotten that there is a university for the deaf in the U.S.A.: Gallaudet in Washington. This is the symbol of a deaf culture. Although this is not the case in France, the awareness that they constitute a cultural community is not absent among deaf French people.

But it is certain that if this cultural logic were systematised, there would be the danger that this kind of specificity would make the deaf community some sort of exception, in the same way that American or Canadian Indians live in their *reserve*, marginalised and treated with indifference and condescension. This is as far as a reference to American culturalism as a way of thinking about disability goes, even in the case of the deaf.

LIMINALITY AND ANTHROPOLOGICAL FIGURES

These various currents of thought have been critically examined by Robert Murphy, who has proposed his own approach to thinking about disability, this time with reference to anthropology. In his eyes, interactionism, with its dual notion of stigma and deviance, denies the specificity of disability. To him, these categories appear to imply the idea of guilt, of transgression, and thus to associate disabled people with criminals and wrongdoers.[9] However, even if disability may produce guilt, for example in the parents of disabled children, it cannot accurately be conceived of in notions related to justice and morality. Murphy is completely oblivious to the current British trend, for the simple reason that he wrote before the literature of Disability and Society could possibly have been known to him. But if I may be so bold as to speak in Murphy's place, one could say that bringing the issue of disability down to a more or less traditional social issue, with concepts like oppression and exploitation, also clouds its specificity. In other words, it is the inverse of the Britons' argument when they challenge the anthropological specificity of the disabled. To my mind, these reproaches are reciprocal, and impossible to decide about at this level. Since Murphy exposes rather than criticises, one has to pick out the argumentation which is opposed to the current English ideas from the positivity of his discourse. Murphy, who was an anthropologist before becoming disabled (chronologically speaking, at least), had studied Van Gennep (1981) on rites of passage as well as Turner (1969) on threshold – or liminal – situations. Here he found a model which allowed him not only to understand his personal experience, having become first paraplegic and then quadriplegic, but also the hidden social status of disabled people. In traditional societies, as we know, there is a plethora of liminary and intermediary situations; indeed, every time there is a passage from one status to another. The time and/or the place between the two is opened and shut by *rites of passage*, which include initiations and specific practices. When a child is to acquire the status of an adult, for a given time he or she enters a liminal phase where, detached from a state of childhood by means of a rite, the individual undergoes a preparation for adult life. Before being born into a form of new life, he or she goes through a kind of temporary social death designed to make this mutation possible, quasi ontologically. Once this threshold phase is completed, the person enters into the status of an adult by means of new rites of passage.

Turning then to disabled people: in the representation of their environment as much as in institutional practices, they too are placed in this intermediate situation between two *valid* statuses: the former one – that of the others – and that which would have to be regained – which, supposedly, is what the others hope for. But the difference as regards liminality and threshold positions as recorded by anthropologists in a number of societies is that the disabled are condemned to remain in the in-between state. They have left their normal status due to the after-effects of disease or accident (possibly with stigmatisation) and, often quite literally, they have also left some special place they have been at: hospitals, rehabilitation centres – just as formerly consumptives went to the sanatorium (think of Thomas Mann's *The Magic Mountain*). And even when they return to take a new place, or the one that was formerly theirs, they continue to be seen and treated as remaining in an in-between situation. Thus they are neither rejected, nor fully accepted, nor sidelined, nor integrated; they are

> neither strangers nor completely familiar. Neither found guilty nor treated as completely innocent, because they are embarrassing and at fault for disturbing the peace of mind of a society dreaming of men and women with zero deficiencies. Neither slaves nor full citizens. Neither totally subjugated nor free. (Gardou 1997, our translation)

There has indeed been a separation from the *ordinary* world, there is threshold, but the new aggregation just does not form, or only very badly (and sometimes with ambiguous pseudo-rituals, like the famous dinner described by Murphy where he is fêted as if returning to the university, but where everyone conspires to make him into a survivor, someone rescued from a disaster, rather than an academic restored to them; p. 109 ff.). There is a crystallisation, a gelling, of the intermediate situation.

Admittedly, Murphy's analysis is applied to a great many situations. *Sheltered* structures (centres of assistance through work, sheltered workshops, medico-professional institutes) are typical of liminality, but so is the whole of positive discrimination as everday behaviour. *However, above all it is the highly pertinent introduction of the anthropological point of view which marks a decisive step in the thinking on disability.* And even if one rebels against the conditions imposed on disabled people, it is this point of view which makes it impossible to think of it as oppression or as originating solely from whichever form of social organisation, be it based on liberal or capitalist principles, or as simply segregationist and excluding. Murphy, however, leads the gaze to systems of thought, and indeed to the invariables – relative to impairment – which plunge into the depths of civilisations. Deformity of the body, troubles of the mind, loss of senses, have always worried social groups, just as sex, power, change, death and ancestors have. There is no culture which has not worked out an explanation, a vision, in short, an *anthropology of infirmity*. Without wanting to seem unduly pretentious, I believe that this is the strength of what I started to glimpse in my first book (Stiker 1997). This point of departure and this point of view both seem fundamental to me, because they make it possible to affirm a certain specificity in the fixed issue relating to disability today, one which cannot be solved by the mere *social question*, and which has taken the name, unhappily in the opinion of some, of *exclusion*. The issue of relationships between men and women is, partly, not dependent on economic conditions or even on social givens alone, because a sexualised relation is also, initially, one of emotion, fantasy, desire, etc. To be sure, there is no emotion, fantasy or desire that could not be found in history, and the imagination, for an Egyptian in the second millenium before ours, was not the same as it would be for a French person at the end of the 20th century. However, this is no reason to reduce issues of sexuality to the purely socio-economic; the social frameworks of the imagination by no means negate its specificity. And so it is with disability. It brings with it its share of representations linked to our fears for our species, our guilts related to the practice of our sexuality or to shady aspects of our ancestory, our narcissitic wound, etc. Together with certain psychoanalysts, I would emphasise once more how important it is to listen to the bewilderment and stupefication of the parents of disabled children: their desire to kill them, their inability to mourn, the well-known *backlash* of older problems which re-emerge, the overprotection or rejection, the desperate search for reasons, etc. in order to see that this is a completely different thing from social oppression or economic deprivation. In his own Japanese culture Kenzaburo Oe, winner of the Nobel prize for literature in 1994, expresses something universal when a character in one of his novels (Oe 1988; see also Oe 1977) whose wife has just given birth to a child with a cerebral hernia says of himself, under the accusing eyes of the doctor, I am the father of a monster. A monster which comes to accuse and question his project of leaving for Africa, his self-image, in short which puts fetters on all aspects of his life, leading him to drink and to frequent prostitutes, which prevents him from going to see his wife and the child, etc. Only after a painful and arduous journey does he finally transform himself and confront reality.

The constant element here is the triggering of a certain symbolism. However, each culture evidently produces its own.[10] In all societies one could term religious – that is, all societies up to the modern age which consider themselves to be founded, in a heteronomous fashion, upon a relation with a beyond, an exterior, a transcendance, a divinity – representations relating to impairment view it predominantly in terms of a message. This message originates in the beyond, and is thus linked to a divine wish or a punishment; it almost always entails some kind of relation to a transgression (but not necessarily to guilt) and above all it demands a symbolic response appropriate to the message.

Some Figures from Earlier Times

The meanings are heterogeneous and varied, depending on the era; but up to the 17th century the disabled found themselves in a situation which I call *meta-social.* This situation conferred on them social tasks or positions, or perhaps rather social functions, belonging to a symbolic order beyond the economic, the legislative or the daily. In ancient Greece, congenital defects were viewed as *malefice*, evil spells. Birth deformity is a warning sign from the gods addressed to a particular group which was both at risk of change for the worse, and which had offended. Deformed infants were displayed, "because they created fear; they were the sign of the gods' anger and they were also the reason for it" (Delcourt 1986: 22, our translation). What is significant is that the malformed newborn is supposed to be returned to its senders to show that the message has been received. The ensuing practice is what the Greeks called the displaying of these infants, reserving a very particular word for it: *apotheosis.* At the decree of those responsible for the city, children displaying anamolies (webbed fingers, incomplete or deformed limbs) were taken outside the social space onto vacant ground, bogland or onto water, where they perished. Not killed outright, but left to the mercy of the gods. Those who survived became, at least in the collective imagination, people of superior significance, that is if they didn't fall into the hands of slave-merchants or traffickers in prostitutes. Greek mythology shows this super-signification of the disabled admirably: there is Oedipus, Hephaestus, Hermaphroditus, Philoctetes and Tiresius, to name but some of the best-known figures.

If we turn our attention to Hebraic culture, disability appears as *impurity.* Any infirmity, here, shares the burden of showing what separates the divine from the human with other individuals and other situations. In fact, in Leviticus, which deals with the sacerdotal caste, sons of *priests* who are born with disabilities are excluded from the cult. They are not permitted to present sacrifice. When approaching the presence of the divine, one had to be hale, unblemished, and pure (Douglas 1967). God is wholly transcendent and is not involved with the world of men. He is present at certain times in certain places. Hebraic thought, then, gives the conditions for the reception and the *meeting*. The *cult interdict* is a strong one, but it is limited and does not involve any hasty practices. On the contrary, the Hebraic ethic constantly commands that the poor and infirm be treated with generosity and compassion, although there is no institution earmarked for them. Disability participates in the demarcation of the sacred, without exclusion from society.

If we look now at the medieval period, we will come across two different major figures of disability. The first I will call the system of *buffoonery*. In this term I include both the mystic elevation and the elevation of the buffoon (or clown, jester or fool, translator) at court. In the latter case, the disabled people (mainly dwarves, the lame, deformed or feeble-minded) had attributed to them the function of poking derision at others. Their disability was a permanent manifestation of the fragility and human arbitrariness of order and of the established powers. It gestured at a world turned upside-down, and it conferred the privilege of saying what no-one else was allowed to say, particularly to the powerful (Maurice Lever 1983). In what I have called the *mystic* case, the disabled person is considered the *location* itself of the contemplation of God and as the extended incarnation of Christ. An image of transcendance brought up close, it leads us towards the beyond, in the same way that the buffoon points to an inverted world. The fool rubbing shoulders with princes or the lepers embraced by St. Francis of Assissi have in common that they tear away the veil of appearances, the here-below, and show us the inexpressible, the *meta-worldly*. The buffoonery of disability plays the role of mediator between two worlds and questions the foundations of society.

Equally, the medieval epoch, which is a harsh one for the disabled, does allow some tolerance. And even if the disabled person is considered to be an expression of the demonic (as in certain forms of *madness*, without saying that madness and possession are one and the same), it is rather because they are signs of another world that they are rejected.

Disabled buffoons speak of an *elsewhere*, they are able to judge the *here and now*. They participate in another world, which is also a different world. The Middle Ages on the other hand developed another figure of disability. It is one of the forms of *poverty*. To this extent, the poor man is my fellow, because his is the face of Christ. In medieval times, the poor man is a sort of image connected with Christ, but we are all brothers in Christ. That he be welcomed and shown charity, then, is imperative. The poor received hospitality from a multitude of foundations created by rich laymen, princes, or bishops and abbeys; they received shelter and alms which ensured the others' salvation. This charity, in the noble sense of the term, did not change the condition of the poor and beggars, amongst whom again most of the disabled were to be found. For although giving alms was a chance to ensure salvation, and obligatory, the dominant theological vision conveyed a passive attitude in the face of suffering, inequality and underprivilege. Indeed, the world had left the creating hand fully formed, and was a work of divine wisdom. It is we, human beings of little understanding, who cannot comprehend God's grand designs. Thus while medieval society did not set up any discriminatory processes against the disabled, it also made no attempt to overcome or reduce discrimination.

The Anthropology of Disability

I do not intend to give further examples; I have, I believe, indicated clearly enough that disability cannot be analysed unless placed in and translated into the cultural imagination of specific cultural contexts. Even in our modern, autonomous societies, founded on scientific reason and social order, disability has appeared in various anthropological guises – the last incarnation being *handicap/disability*. This social construct reveals a symbolism which goes way beyond a simple, or single, *social issue* in every respect. Let us briefly consider this contemporary anthropological figure.

First, certain events must be recalled. By the turn of the century, industrial accident casualties had become a major problem. Industry, unregulated and exploitative as it was, had injured and broken a good number of citizens. It was going to have to come to terms with the idea of social responsibility. In future, therefore, there would be an obligation to repair and later to compensate for the injuries produced by risks at work. This would no longer be the sole duty of proprietors as individuals but of the nation as a whole. Efforts would thus progressively be made to ensure victims of industrial accidents were not deprived of a place in economy and society. Here one should read Francois Ewald's *L'Etat providence* (1986), in which he describes this quiet but profound revolution in a society which has succeeded in installing a new social deal based on ideas of collective responsibility, social insurance, reparation, compensation, in short everything that results in the grand ambition of *social security*, undoubtedly one of the most solid foundations of modern democracies. But what I would like to add to Ewald's description is that the main reference point of these developments was the new wave of disabilities created by the industrial *fact*, a social fact which was itself claimed to be central. Or in other words, not only can it be seen that social issues always originate in central mechanisms which make the entirety function, and are accepted by everyone, or almost everyone, but it can also be seen how a social issue can also originate from a group posing an urgent question. This is secondary in regard to my main concern here, however. What emerges for me from the issue of industrial accidents is the beginnings of a new view of disability, which henceforth is to be viewed as it were through the prism of industrial accidents. From this point on, all disabilities are increasingly to appear as pertaining to collective responsibility, collective solidarity and *accidentology*, if I dare use such a barbaric term; that is to say, disability becomes denaturalised in order to become socialised. It will be a social issue as much as one of impaired health. In future the state will find itself implicated, something the revolutionaries foresaw and indeed wanted, although none of the legislation was implemented.[11] The disabled person is no longer a poor wretch marked by fate, basically faced with dependence on public assistance if not subsidised by individual charities; now he or she begins to have rights to collective solidarity, having been the victim of progress itself.

A second event reinforced this anthropological emergence: the great slaughter of the 1914–1918 war. This applies particularly to Europe, but was not without consequences in North America, which, in the course of the century, was to be drawn into murderous global conflicts. Once again, nations found themselves confronted with a great mass of men broken by *their countries*. The social costs made themselves felt: among others in the form of collective guilt and the economic imperative not to exclude agents from production, ones who moreover laid claim to a job and the rights to reparation and compensation as well. From the first years of the war, to take the French example, a ruling was established in order to provide access to services and establishments offering professional rehabilitation. A return to activity became an imperative and a demand. To the quiet revolution of social security, the injured of WWI had added the desire to return to the economic and social mainstream; a return to earlier times, or simply to the midst of others.

The third significant event is the condition and the claims of TB sufferers. Tuberculosis is, as we know, not only contagious, but also frequently seen as linked to certain social, economic and hygienic conditions. It is thus viewed as a social issue as much as a sanitary one. Once again, the great number is the determining factor, apart from the fact that all those returning from the sanatoriums wanted their share of their interrupted education or abandoned jobs. Finally, I would like to mention a fourth event, albeit one needing more delicate treatment, namely the consequences of compulsory education. Even if special needs instruction originates just as much, if not more, from the problem of hospitalism as from *difficult* children in schools (Vial 1990), the fact remains that the progressive normalisation of school, with its stages and levels, assigned and measured by Binet and Simon's famous tests on the metric scale of intelligence, throws into relief all those who for one reason or another do not adapt to this standard schooling. Here again, the preoccupation with reintegration at all costs will become ever greater.

Thus a new wish arises in society: those who are removed from the life and concerns of the many due to disability of whatever kind, are to be re-integrated. In the 20s, there was a change in vocabulary. While words which I refer to as *defective* (in-firm, im-potent, in-capable, im-becile, in-valid, etc. etc.) were not banished, words relating to re-turn (re-classification, re-adaption, re-integration, re-insertion, re-habilitation, re-education, etc.) appeared. Still more than this language, the proliferation of services and bodies proclaiming loud and strong their aim of a full return to society, is a significant indicator of the new intention. It is of course evident that the gulf between intentions and demands on the one hand and the reality of the apparatuses and financing on the other will remain. But in an analysis of sociological and historical orders such as the one I am outlining here, it is important to emphasise not only what is efficacious, but also what is put into place in social representations, in opinion, in the *subjectivation* of those concerned. In this, I believe I am very close, in terms of method, to what Gladys Swain and Marcel Gauchet threw into relief when, confronted with the unilateral Fouldcaldian thesis of exclusion, they identified the logic of *in*clusion at the very birth of Pinel's psychiatry, linked to the political thought of the end of the 18th century (Gauchet/Swain 1980). By the same token, there is a plentiful share of contradictions engendered by this new representation of the disabled. There is the production of *new* populations of the disabled, either because the risks in society are new (road accidents, sport, drug addiction, etc.) or, although life is generally safer, because those who would have died some years ago survive and live longer. Disabilities are becoming ever more severe or complex (think of the critically ill saved in extremis from death by the emergency services or by surgery, or else of infants who remain alive with multiple defects). Yet these increases are taking place in a society where unemployment is rife (consider all those who, having been lost their work as a consequence of absence or a health-related incident, never again find a suitable position). Dare I point out that there is a *contradiction* between a desire for normalisation and the growing number of severe disabilities, many of them due to advances in medicine? I am thinking here of the prolonging of the life-expectancy of young myopaths and trisomy 21 patients, as well as of saving premature infants or those who have had difficult births, who then become those known as the poly-disabled. Nevertheless, whatever the contradictions, a completely new picture of disability was created during the first half of the 20th century, which has found its best expression in the terms *handicap* and *handicapped* themselves.

As everyone knows, the word was borrowed from the field of sport, and more particularly, from the turf. In sport, a handicap corresponds to a measurement of unequal performances by competitors engaged in competition. Once the competitors can be compared, the handicapper determines how their chances will be equalised in the competition. In horseracing, at least in that type more precisely called *handicaps*, the *handicap* consists either of a weight or of an extra distance imposed on the strongest horses.

However, there are also equalisations which give advantages to the weakest. It is not primarily a notion of advantage or disadvantage that is significant in understanding handicap in sport, but one of equalisation, so that the race or competition takes place in conditions that make it possible to perceive the competitors' purely personal efforts and abilities. It also ensures that the competition is interesting to watch and not a foregone conclusion. As one author puts it, "Whatever the discipline, the handicapper's dream is to to see all the competitors passing the winning-post together" (Alain d'Hauthuille 1982: 63, our translation); and again, "For each race, the programmes set down the conditions to be fulfilled by the competitors. The criteria are chosen in such a way as to manage the equine population as well as possible by giving every type of horse in turn its chance" (ibid.: 61). In sport, and particularly on the turf, the original sense of hand-in-cap plays no role at all. The game of chance which bore this name has disappeared, having served to establish betting at the racetracks. Referring to this meaning of *handicap* is somewhat whimsical, since all Western dictionaries and documents show the shift away from the idea of *hazard* to the sporting sense, and from the sporting sense to the *medico-social* sense. On the other hand, the various shifts in meaning can all be explained in terms of parity, the comparative judgement of the value between two objects.

What was the reason for the shift from sport to the domain of human individuals suffering from disabilities? Note first of all the chronology: up to the 20s, dictionaries only give the horseracing sense. Then, a meaning designated *figurative* signifies an obstacle or an inferiority; one country is handicapped in relation to another as regards industry, for example. The sense designated medical or medico-social does not appear in France until the 50s or 60s, that is, very recently. In the United States however, from the turn of the century there is evidence of journalistic use of the word *handicapped*, designating all sorts of people afflicted with all sorts of defects and in a difficult social or professional situation. The invasion of this vocabulary of handicap seems to date from the new social deal regarding impairment and invalidity, but the usage increased very rapidly from the point I spoke of above in the context of the birth of rehabilitation when they acquired the means to strive for maximum equality with the able-bodied and for *normalisation*, for the chance to *return to the race*. The metaphor corresponded perfectly to what was required: to make people become *performers* on the social stage once more, to compensate them, to make them able to participate and to develop the techniques needed for re-education.

A metaphor which employs a sporting term in the domain of human health is transformed into a veritable model of treatment. From the mass of the inhabitants, a particular group is marked out and *adjusted*, just as the group of racehorses is extracted from the whole of the equine race. The goal of this extraction according to category is the improvement of this group (the goal of horseracing for the equine race). Once marked out, this group must be *classified*. Just as there are purebreeds, trotters, etc. so there are physical, mental, sensory, etc. handicaps. For each of the categories furthermore, specific techniques and types of training – and of remedial measures – are provided; thus there is a pronounced *specialisation*. Finally, there is a *test*, a reclassification/rehabilitation, a reinsertion, and as soon as possible, participation on an equal footing in the common competition. If it can be accepted that when a society uses a *play on words* or *language game* it does so because the game corresponds to its *form of life*, to refer to Wittgenstein, then one sees the close equivalence between the language of handicap and the dominant idea of our society, namely that of *performance*. Sport and horseracing, with their organisation of races and competitions and the passion they provoke, symbolise, condense and caricature contemporary society: industrial, commercial, based on appearance and image. One has to perform well, be competitive and media-oriented. By speaking of the phenomenon of disability in terms of that of horseracing, our culture is *integrating* disability culturally and ideologically, and showing that it, too, can no longer escape the demands and *laws* so valuable to all of us. It is our way of *taming* and reducing the gap represented by the out-of-the-ordinary as much as possible. People with infirmities, having become handicapped, are seen as citizens to *per-form* – to use an old French word which has passed into English. The disabled/handicapped are subjects who, at least in principle, can and must succeed. The image of the handicap is a way of thinking about non-conformity within the limits of our productivist and technological habits of thought; a way of thinking that makes it admissible to us.

This however is not enough. If the passion for normalisation and integration is indeed the point of view from which our treatment of disability (statutory, financial, institutional etc.) can be made intelligible, the consequences could be completely different. In the first place, in wishing to integrate the disabled (in both the above-mentioned senses) one can forget. For at the heart of this desire for integration lies a grand gesture of denial, of effacement, of erasure, as if it were possible to stamp out the excrescences, the warts and the dross of society, as if it were possible to *reduce disabilities* in the sense of diminishing them of course, but also of making them disappear. On the basis of this laudable intention, one might be tempted to forget the difference, and indeed also the suffering and the specificity of the experience. By reducing the question of the meaning of disability in human terms to one of a surmountable obstacle, one may also re-exclude in a subtle way, by in-difference.

I believe furthermore, like Murphy, that a certain way of speaking of disability and disabled people is ultimately a cover-up operation. The end result of the model and the *culture of handicap* would be a denial, however paradoxical this may appear in the eyes of those who believe that they are stigmatised and impeded. My British friends must be warned. Those who want to bring the issue of disability completely out of its enclave could possibly be in the process of repeating an *act of denial* which, at heart, global society expects. If the *medical model*, to return to their vocabulary, is so pernicious because it could keep them continuously sidelined, the *social model* could be a subtle attempt to make them disappear altogether. For this dual reason, surely, the term is being disputed all over the place; and also, surely, we are watching the end of a model, the end of a cycle of thought, and the end of an anthropology which first appeared in around 1900.

FORMAL MODELS

The course of the historical anthropology of which I have just sketched some elements in order to show that disability is something produced by habits of thought, shows that there are several orders of difference within which the groups concerned are contained. I say *orders of difference* because it always concerns situating an oddity, an aberration. Perhaps one could speak of *alterity*. I believe it is possible to reduce these orders of difference to three large models.

There is a hierarchical model, which seems to me the most pertinent with regard to European history. Here the specificity, the difference, is recognised and may even be accepted. But according to the logic of genus and species, the common genus is defined as humanity, within which there is a series of points of view corresponding to at least one distinctive trait. From the point of view of gender, it is male or female, man/woman. From the point of view of biological conformity, the distinction would be able-bodied/disabled. These established species are not however considered equal. Rather, they are situated on a scale of positions and values. This is a way of integrating differences, since they are kept together in a coherent order, but also in a system of submission. For example, men and women represent two ways of being human, but the man must dominate the woman because the supposedly *natural* roles attached to these two ways of being see to it that one of them has priority, dignity, greater importance (a political role versus a domestic role; a productive role versus an educational role; authority versus emotion, etc.). In his *Souci de soi*, Michel Foucault shows that the relations between the sexes in ancient Greece (like the relations between men and youths) are dominated by social position, which determines rights and liberties. This is a type of cohesion by hierarchisation. The Catholic church offers us the purest model of this conception. Clerics are different from the laity, but enjoy a dominant position. Christians are a genus, but within this genus there are two major species, the clerics and the laity; and in each of these species (which may in their turn play the role of the genus) there are subspecies. The clerics are divided into bishops and priests, the laity into consecrated laity who are not priests (e.g. monks or nuns) and the laity in the world, these too being in their turn men and women. So a tidy pyramid is formed, from the summit where the clerics are found, to the base, where the *simple* laity is placed. This neat earthly hierarchy is supposed to correspond to a no less neat heavenly one. But all the differences are in their place.

The organisation of disability as poverty is of the same order. The disabled poor were accepted in medieval society, for they were a part of the great medley present in a world received from divine hands. However, they were only a part on condition that they stayed in their place; the poor definitely being poor. They had their role and their place but they were at the bottom of the social scale. A disabled woman comments acerbically that this organisation may still be met with today, writing:

> It is the system that puts you in the position of a slave from your birth or your accident onwards. You have to have an attitude of gratefulness and submission. You will never be able to really express yourself. You will always have the tendency to make yourself forgotten, to apologise for existing. You have to be thankful for surviving. (Auerbacher 1982: 155ff. our translation)

The hierarchical model makes it possible to stifle the differences by an initial acceptance of similarity, but one which is strictly controlled. It is undoubtedly a way of consolidating differences which already exist. This recalls Castel's analysis once more, when he shows that the disabled are always exempted from work and assisted. They are not excluded, but their inferior place is well-established.

There is a second model that is sometimes encountered: that of juxtaposition. Undoubtedly more common in Anglo-Saxon countries, it revolves around a certain sense of tolerance and of accommodation. They are what they are, we are as we are, such is their culture and such is ours. We will not seek either to subjugate them nor to inferiorise them, but we have nothing to do with each other. The recognition of difference is pushed so far that each one stays on her or his own, a stranger amongst a collection of strangers. A certain form of nationalism derives from this model: strangers have the right to exist from the moment they stay out of our own space. There is no integration. It is a puzzle or mosaic. Although this model may be allied to a form of democracy, as can be seen in the multiculturalist thinking of the U.S.A., pushed to its limits it in fact destroys all common space, and in the interior of a nation it destroys the foundations, just as in supranational contexts it destroys all organised space, like the UNO or the European Community. Federalism attempts to surmount the inconveniences of this model, from which to some extent it emanates. When the groups, classes or cultures are simply juxtaposed, then an oppostion of values appears, which shackles the social order and above all ossifies the existing social structure. The model represents a possible tendency in the treatment of the disabled rather than a model actually ever applied, but it could come to this *Indianisation* of disabled people that I have mentioned. Many people would not be disinclined to use this model if it meant a purification, a *tidying up* of their space!

Representing almost the opposite of this model of juxtaposition, with a possible link to the hierarchical model, there is a normalising model. It has common values, common objectives, rules of behaviour, averages which must be aimed at. The work consists in doing everything possible to join this consensual, uniform whole. This is the model I described in the progressive establishment of the field of *handicap*, and this is what is at the basis of the immense attempts at rehabilitation, re-education, etc. In this model, we are on the way to rigorous integration: each element must conform sufficiently to be included in the machinery of the whole. However, lurking here is a powerful denial of the *other*. At the very most, there may only be some differences, it being understood that those who are tolerated are also restrained.

It seems to me that, more or less, all three forms of relationship have, by turns or simultaneously, played a part in the way the disabled are treated, and that their lot has always see-sawed between subjection, indifference and denial. What remains to be created is another model, and this is the challenge to all truly democratic forces: to establish relations which impose and respect specific terms, invent various combinations of terms and take alterities into consideration. If an image of such a model is wanted, it can be found in language: here all differences (since there is nothing but difference) are opposed and related to one another to create meaning, meaning which is always open because the combinations are infinite. Each language, moreover, however unfamiliar, may nevertheless be translated into another language; not transferred completely, but translated, with the inevitable distortions that entails. Disabled people cannot be reduced to a mere social identity (deviants, fringe group, etc.), nor to an identity based on how able they are. Their being-in-the-world is unique (differently unique, depending on the person and the disability), but they are able to translate our experiences into their own and vice-versa, just as they are, socially, a separate case, but one which can be translated into other cases: and other cases can in turn *read* themselves in their case. In other words, one should not reject all notion of alterity, on the grounds that the idea of difference implies too strongly that of similitude and could actually exacerbate conflict and stigmatisation. Once this is achieved, a common, shared space can be set up where there is no longer any hierarchy, a space where separation would mean being *reduced*. This, I believe, is what Diderot perceived in his famous letter, when he showed, though not in so many words, that Saunderson or the blind man of Puisaux were *anthropological varieties*, or perhaps it would be more precise to speak of *variations*, such as those that are embroidered onto a basic theme in music. This was expressed by a literary critic, severely disabled himself, at the end of a congress devoted to disability in literature:

> In the light of everything that has gone before, it is becoming most evident that traditional images of the disabled transported by literature contribute very little to creating the kind of attitudes thanks to which a world would be possible in which the disabled could be recognised as not being *some absolute and intolerable other*, but rather as an extreme among the *others* of human reality, a world in which differences of perception and agility of movement would not only mark the separation between one individual and another, but also between the various stages of a life, from the total dependence of the infant to the progressive decrepitude of old age ... And on the psychological level, even the most debilitating infirmities would be perceived not as aberrations but as a variant of the infinite diversity of the human norm. Even pain and death would be met face on, with sadness or joy, rather than avoided with embarrassment, distorted by terror, or denied by pity. (Fiedler 1982, our translation)

ON THE SOCIAL UTILITY OF DISABILITY

Disability can be thought through and thought about, and anthropology, in its historical dimension, provides an adequate framework for this, emphasising both permanences and cleavages as well as the specificity of a dimension of societies which cannot be reduced to others.[12] Taking it to extremes, one could say that the permanent idea across Western cultures is that of limits, boundaries, thresholds; disability always takes its place, symbolically at least, on the line of demarcation, in a position of passage between two worlds or between two statuses or two groups; and this is true from Greek myths to current practice. In contrast, the modalities and the precise contents of these confines and limits vary enormously. But at the same time, it has been possible to see the decisive nature (at certain moments) for the whole of society of the way disability is considered. It is as if just here there is a nodal point (and not the only one, evidently) or a crossroads, to use a different image, from whence a general orientation can be obtained.[13] The confrontation with a specificity which cannot be sidestepped means a decisive position for the group; or, to paraphrase a well-known saying: *tell me how you treat the disabled, and I'll tell you who you are.*

NOTES

1 The introduction of the word *handicap* in the French translation is contemporaneous with an orientation in favour of disabled people becoming the rule.

2 At the Ecole des Hautes Etudes en Sciences Sociales, under the auspices of Serge Moscovici and Denise Jodelet, a group of researchers has been working on the topic of disability in France. Apart from Jodelet's own book (1989 and 1995), which touches on the area of disability, others which should be mentioned are: Giami 1988; Colette Assouly-Piquet and Francette Berthier-Vittoz (preface by Monique Schneider) 1994; J.S. Morvan and H. Paichler 1990; Sciences sociales et santé, vol. XII no. 1, March 1994, Handicap: identités, représentations, théories.

3 The book appeared in 1965 under the title *The Established and the Outsiders*. The word *exclusion* in the title of the French translation is undoubtedly due to the current French context. It is regrettable, since it gives the impression that the work is nothing but a response to an ephemeral current trend.

4 It is not possible to say much on the subject here, but beyond Elias' concepts questions arise, in regard to groups like that of the disabled, of the violence unleashed by the other by the sole fact of his alterity, of his presence, of his intrusion into my existence or into social existence as such. This goes to show just how much the issue of infirmity is a privileged place of observation, as much in terms of the psyche as of the social configuration.

5 Korff-Sausse 1995 under the direction of Maurice Dayan, or Sausse 1996. This approach is worthy of more extensive treatment. We have chosen to concentrate only on social aspects here, however.

6 The prolific author Colin Barnes writes: "The rise of the institution as a means of both social provision and control coupled with the individualisation and medicalisation of social problems under capitalism resulted in the emergence of the individualistic medical approach to disability. For Oliver this personal tragedy of disability has, in turn, achieved ideological hegemony (Gramsci 1971) in that it has become translated into common sense and everyday assumptions and beliefs. It is evident that unlike the work of their American counterparts these accounts suggest that the basis of people's oppression is founded upon the material and ideological changes which occurred as a result of the emergence of capitalist society." (Barnes 1997: 6)

The group working along these lines is a large one. One could however single out Mike Oliver for mention, with his *The Politics of Disablement* (1990) constituting a landmark publication.

7 These insights, coupled with the radicalisation of young disabled Americans in the Independent Living Movement (ILM) led Gerben de Jong to proclaim that attitudinal and environmental factors are at least as important as impairment in the assessment of disability. Colin Barnes op. cit. p. 6 (cf. De Jong 1983).

8 Between the Abbé de l'Epée who died in 1789, who organised sign language, and the – sadly – famous Congress of Milan (a meeting of institutions for the

instruction of the deaf in 1880), the deaf had developed a *deaf culture* (with many gatherings, meetings, banquets, access to knowledge etc.). With the prohibition on the use of sign language in instruction pronounced at this congress, a linguistic minority was going to find itself oppressed (the word is apposite here) in its expression. After all, even if a language alone is not enough to define a culture as such, it may be its major element, since its semantics have their own stamp, their own way of conceiving, symbolising, etc. As regards the history of the deaf and their language, I would refer the reader to the following publications: Lane 1984; Presneau, Saint Loup and Bernard Mothez 1996 have, with the emphasis on vocabulary, made important contributions.

9 In one of the first articles published, in which Murphy's position was discussed at some length, the author Marcel Calvez judiciously takes Edgerton's work, going back to 1967 (with *The Cloak of Competence. Stigma in the lives of the mentally retarded*) as a point of departure.

There is a finely-woven complex of social contexts in which the perception of mental retardation as an immovable human condition runs side by side with charitable principles towards those thus afflicted. This takes the form of assigning them a social niche in which they are protected from the vicissitudes of life through the connivance of others; they accept likewise the status which is assigned to them. (Calvez 1994: 71)

Thus there are mechanisms quite unlike that of stigma, which indeed even obstruct it. This perspective is a good introduction to Murphy's position.

10 In the few brief paragraphs that follow, I can only hint at what I have written on more extensively in various publications. The concern here is merely to make the reader aware of the force of an anthropology of disability opposed to all attempts to *reduce* it.

11 In fact, legislation of this type was seen when in the law of 1905 on the elderly, the disabled and the chronically/terminally ill was passed. See for example Charoy 1906.

12 At this point, I would like to comment on an aspect of Robert Castel's work in *Les métamorphoses de la question sociale, une chronique du salaria*t. One of the great divisions in the social question is the distinction between those obliged to work and those exempted from working. In the latter category, which the author calls *handicapology*, one finds various groups at different times, but the category remains fixed, regrouping those who are not able to provide for their basic needs by themselves, and who are thus receiving support. In this category one always finds the disabled and infirm, together with the old, and it is not for nothing that Castel resorts to a neologism derived from *handicap* (pp. 29–30). It is illuminating to understand that for centuries the disabled had been exempted from working, and that it was something of a revolution when the wish to put them to work as a means of integration first arose. But in this two things should not be concealed from us: that the disabled are the targets of *projections*, no matter how diverse, and are not only a part of the poor; they are invariably *good to symbolise*, to plagiarise a

formulation of Lévi-Strauss', that the revolution I am speaking of is exemplary of society in its entirety, which knows only *homo laborator and homo faber*. On this last level they are still symbolic (admittedly in a different sense) of industrial and commercial anthropology.

13 In addition to the example of industrial accidents, the great turning-point which Diderot's famous *Lettre sur les aveugles à l usage de ceux qui voient* represented in the 18th century ought perhaps to have been discussed. At the same time as the problem of blindness (with the well-known problem of Molyneux) was to be found at the heart of philosophical ideas about knowledge, it was also to be found at the heart of educational and social issues. This made the first major initiatives for equal chances possible: Valentin Haüy, l'Abbé de l'Epée, Itard (cf. Swain 1982).

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