BIO-MEDICAL VERSUS INDIGENOUS APPROACHES TO DISABILITY

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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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