

## SOME CULTURAL REPRESENTATIONS OF DISABILITY IN JORDAN: CONCEPTS AND BELIEFS

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### 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'el verse 97; Khan 1979: 1033); and which dictate amputation as the punishment for outlaws (Ali 1994; Al Mumtahirah 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 Per-

sons) 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.<sup>1</sup>

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 verses 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<sup>2</sup> 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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