CHAPTER 10

Definitions of Disability and Disability Policy in Egypt

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Introduction

In this chapter, I will show, using Egypt as a case study, how definitions of disability in developing countries are still dominated by a broadly individualistic medical approach. Yet despite this dominance, there is little consistency in usage, particularly in official data. This has resulted in a rather limited knowledge of the numbers of disabled people in Egyptian society. This lack of clarity inevitably influences the work of politicians and policy makers when they are formulating laws and policies directed at services and support for disabled people.

The significance of exploring recent policy developments in Egypt is that it is one of the first countries in the Middle East to address the support needs of its disabled citizens. As a result, its experience is considered highly significant in neighbouring countries, if not developing countries more generally. I will begin with an examination of the major causes of impairment and disability in an Egyptian context. Attention in the following sections will centre on, first, the various interpretations of disability in Egypt and, second, how they are reflected in Government legislation and policy.

Major causes of impairment and disability in Egypt

In Egypt, there are two major causes of impairments – economic and social. As a developing country Egypt suffers from widespread poverty. This is associated with unsanitary living conditions, lack of access to safe drinking water, and inadequate means of garbage disposal. All these factors are the cause of communicable diseases leading to various impairments (Qandil 1989: Teçke et al. 1994). More specifically, these diseases place a strain on

the physical and mental growth of children, which may lead to permanent impairments (El Safty 1994; Fahmy 2000). As stated by Boylan:

> No vaccine exists that can immunize against hunger or malnutrition. No substitute exists for safe drinking-water, which is currently not available to 50 per cent of the world's population (1991: 21)

Another major cause of impairment in Egypt is malnutrition. Because of the poor economic income generated in rural and lower-class urban areas, malnutrition is very common. It affects mostly women and children, which puts them at a great disadvantage to fall victims of impairment. Vitamin A deficiency, which causes a very high rate of blindness, is mainly caused by malnutrition (Nosseir 1989; Fahmy 2000). Malnutrition is also very common among pregnant women, and this has a potential effect on the unborn child. It may lead to low birth weight, which affects the physical and mental development of the child and may lead to a form of cognitive impairment or 'mental retardation' (Nosseir 1989). Also, iron deficiency, which causes anaemia, and iodine deficiency, can cause loss of hearing (Scheper-Hughes 1984; El Safty 1994; Fahmy 2000).

Social causes are also implicated in high levels of impairment. One is endogamous marriage. Although there is some debate over the accuracy of the figures it has been suggested that they account for 67 per cent of the total number of people with impairments (El Banna 1989). People usually prefer to marry cousins for a variety of economic, social and cultural reasons. This type of marriage arrangement is very popular among the well-to-do as well as among the poor. However, hereditary factors can result in all types of impairments – sensory, mental and physical. When first cousins marry, these genetic disorders can easily affect their children. In the National Research Centre in Egypt, clinical and genetic examinations were carried out on 100 cases of children with 'intellectual impairments'. The findings showed that 90 per cent were genetically affected by intermarriage among relatives – with 50 per cent involving cousin marriages (Nosseir 1989).

High fertility rates also contribute to the impairment of women and children. In traditional societies like Egypt, families tend to encourage women's early marriage, often in their teenage years. Despite the success of family planning campaigns the prevailing beliefs are that contraceptives damage health or are unacceptable on religious grounds. Thus many women have a long experience of child-bearing. Having children at an

early age and repeating the process throughout the fertility period causes these women to be physically and mentally exhausted. Their general state of health becomes weak which makes them prone to illness and impairment (Hagrass 1994). In addition, children born by younger and older women have various impairments including low birth weight, lower growth rates and other physical and cognitive conditions. Pregnancy after the age of 37, for example, puts the mother at a very high risk of giving birth to a child with Down's syndrome. These practices further contribute to the malnutrition of the child and subsequently their likelihood of experiencing impairment (El Safty 1994). Another widespread social practice is circumcision. In Egypt, although female circumcision is forbidden by law, it is still practised. Again, this results in various kinds of impairment (Ras-Work 1991; Abdel-Salam 1998).

Nosseir (1989) argues that the frequency of impairment is notably higher among illiterate women and their children rather than among those who have had only a basic education. In Egypt, families tend to prioritise education for their male children and only if their financial means are above average do they extend such opportunities to their female offspring. This is quite evident in the national statistics which show that illiteracy among women age 15 and over range from as low as 40 per cent to 97 per cent. Also, it has been shown that there is a very high correlation between women's educational attainment and their level of fertility. This is why recent research suggests that the best health investment that could be done in developing countries is the education of girls (Boylan 1991).

Ageing is another societal problem which may result in impairment. Although Egyptian society is generally characterised by its young population, people in the older age groups are still supported and cared for by their family. As there are no financial or other forms of help provided by the Egyptian Government, the responsibility for supporting older people, whether impaired or not, inevitably falls to younger family members, and, as in the UK, women have most of the caring responsibilities (Boylan 1991). The high cost of medication also poses a major problem for families with very limited resources living in poorly resourced rural and urban areas. Furthermore, violence and war in developing countries such as Egypt are a major cause of impairments. The use of modern military technology such as land mines, for example, has resulted in the injury of many women and children. Those who survive are often left with permanent physical and/or psychological conditions (Nosseir 1990).

Academic definitions of disability in Egypt

In view of the apparent commonality of impairment in Egypt it is important to consider the meaning of disability within an Egyptian context. This review will initially centre on those definitions favoured by Egyptian scholars and policy makers that, in various ways, have impacted on national statistics, laws, and policy formulation. Hence it is important to examine two key considerations that flow from these interpretations. First, it is necessary to explore the explicit and implicit meanings of the terms themselves as well as their meaning within legislation. Second, as the meanings of particular words and phrases change over time, it is useful to consider when they came into use and also their longevity. This is essential in order to reflect effectively on their impact and usefulness in a period when ideas about disability are changing due to the assertion by disabled people and their organisations that disability is a social problem and a human rights issue.

At this point it is important to note that several of the texts quoted are written in Arabic and translated into English by the author. Osman et al. (1969: 183) define the disabled person as:

> Any individual who differs from normal individuals in physical, mental or social aspects to the extent that requires special rehabilitation action to make him/her reach maximum abilities and potentials.

Clearly, as the words 'physical' and 'mental' are used quite explicitly, it may be argued that this definition is limited in scope in that it does not include people with sensory or hidden impairments. Moreover, by referring to people who are 'different from the normal' Osman et al. imply that people with 'physical' or 'mental' impairments are actually 'abnormal'. Here, the meaning of normalcy seems to be shaped by an individualistic medical perspective of biological functioning and limitations. It may be argued too that with the insertion of the phrase 'social aspects', this definition extends to prisoners and delinquents since these groups are usually perceived as in need of rehabilitation services. Significantly, there is no reference whatsoever to any environmental, cultural or social influences on the process of disablement.

Another definition is given by Abdel Nour who defines the disabled person as:

> The citizen that one or more disabling barriers have resided in, which weakened his/her ability and made him/her in serious need for outside help or institutional support based on scientific and technological basis to render him/her to normal level or as close as possible to normal level (Abdel Nour 1973:157).

As in Osman et al. (1969), the author identifies disability as coming from within the person (personal tragedy) and not from outside (Oliver 1990, 1995; Morris 1991; Lunt and Thornton 1994; Davis 1996; Hagrass 1998; Sapey 2000). Furthermore, when he mentions that the disabled person is the one who 'needs outside help' he is alluding to other members of the population. This sidesteps the fact that everyone needs outside help to survive.

In common with many interpretations these two definitions do not appear to distinguish between impairment and disability or the biological and the social. Impairment and disability are treated as if they were the same thing. As in conventional western thinking individually based functional limitations are presented as the cause of disability. It is quite evident that there is no clear-cut line between impairment and the person. The two are one. Both definitions implicitly if not explicitly imply that that some form of medical/rehabilitative interventions is the only way to resolve the problem of disability, and that the disabled person must strive to achieve normality.

The assumption of abnormality or 'otherness' in these interpretations can be very stigmatizing for people with impairments. This is especially the case for those who are struggling for self-fulfilment in their everyday life by furthering their education or looking for work; activities which are often denied disabled people due to the widely held association between impairment, disability and incompetence amongst non-disabled peers. Given recent developments within the academic arena and disability studies in particular, it may be said that these scholars have adopted a limited and outmoded approach to the disability question. Nonetheless, their work continues to have a significant influence on the writings of other writers working in the disability field, such as Fahmy (1995, 2000) and Ahmed (1997).

These academic contributions include definitions of disability from international organisations such as the World Health Organization (WHO) and the International Labour Organisation (ILO) in their literature to illustrate their awareness of developments at the international level, the influence of those mentioned above remains dominant. Their work

exemplifies Mairian Corker's (1998) assertion that in most disability literature traditional individualistic approaches co-exist alongside the newer more radical ones generally associated with the social model of disability. Moreover as there is no serious consideration of the 'social consequences' of the process of disablement or 'handicap', it may be said that they are more damaging than the WHO's International Classification of Impairment, Disability and Handicap (ICIDH) (WHO 1980). It is also evident that they are unaware of the more recent socio/political approaches associated with the social model of disability.

Therefore, if disability is seen as an individual medical problem or a 'personal tragedy' (Oliver 1990), then disabled people will be treated as victims in need of pity, sympathy and charity. As a consequence, non-disabled people are frequently asked to be sympathetic toward their less fortunate peers and give to disability charities and so alleviate the need for state sponsored support. Furthermore, the perception of disability in the personal tragedy model assumes either consciously or unconsciously that disabled people should be viewed as individuals whose experience is defined by their impairments. Hence, the medicalization and individualisation of disability leads to policies that focus almost exclusively on the individual rather than on the economic, environmental and cultural problems disabled people encounter daily (Oliver 1990, 1995; Lunt and Thornton 1994; Davis 1996). All of which compounds the feelings of powerlessness felt by many people with impairments and, consequentially, inhibits, in various ways, their ability to interact on an equal basis with non-disabled people including parents, teachers, medical and rehabilitation professionals, and other members of the community (Morris 1991; Sapey 2000).

Alternative perspectives

i. Social model approaches

Since the 1970s disabled activists and their organisations, mostly in the West, have rejected the individualistic medical approach to disability as exemplified by the WHO's ICIDH. Instead, they have argued that whilst impairment is an individual biological phenomenon, disability, or the inability to do things, is the outcome of an inhospitable physical and cultural environment that prevents people with impairments from participating in their communities on an equal level with non-disabled contemporaries. An overtly political response to the problems encountered

by disabled people this perspective is now widely referred to as the 'social model of disability' (Oliver 1990; Morris 1991; 1996; Swain et al. 1993; Shakespeare et al. 1996; Barnes 2000).

Increasingly over recent years this socio-political interpretation of disablement has had an important influence on disabled people's organisations across the world. It has provided them with an effective tool with which to bring to the attention of policy and decision makers the limitations of traditional medically inspired thinking on disability. Their aim is to encourage politicians and those in power to formulate new policies and practices in order to give disabled people the same rights and opportunities as other citizens. It is also the case that these arguments have had some considerable impact on governments in developing countries like Egypt, as many now acknowledge the right of disabled people to lead a 'normal' life like others. Yet in many respects these statements seem little more than an empty reflection of those that appear in documents produced by western policy makers as there are no meaningful policies in place with which to make this a reality. Consequently, it might be argued that in Egyptian society, as in many other developing nations, there is little real evidence of the influence of the social model of disability in everyday life.

ii. Lay interpretations

The individual and medical models of disability are deeply rooted in many societies including Egypt. Here, as in many countries, disabled people are generally perceived as objects of charity (Hagrass 1998). At this point it is worth noting that I do not believe that the lay person's view of disability or their responses to individual disabled people are as one dimensional or as rigid as the literature discussed above would suggest. This assertion is based on my experience as a disabled woman living in Egypt. Whilst a charitable response to disability may be seen as problematic in rich, technically developed countries such as the UK or USA, in many nation states it is considered a morally acceptable and proper response to an often assumed insurmountable social problem. Indeed, this perception is easily activated in a Muslim society where religion plays a pivotal role in people's daily lives. Indeed, non-disabled people's responses to people with impairments are influenced by a number of factors. Two important examples are religion and familial relationships. Both need to be contextualized within a society in which Government has up to now proved to be ineffective in responding effectively to the needs of disabled people.

The Islamic faith explicitly encourages Muslims to help the poor and less fortunate in society, including disabled people. In most Muslim societies giving '*zakah*', which may be understood as a form of income tax but in a religious context, is considered an obligation of duty. Moreover, many Muslims give part of their '*zakah*' to various charities, non-government organizations, and disability groups in accordance with their religious beliefs. The extended family is still prevalent throughout the Middle East, and family ties and responsibilities remain strong. The conventional division of labour in this type of family structure requires women who do not go to work to be responsible for the care and support of children and older and disabled family as and where necessary (Teçke et al.1994; Hagrass 1998). Moreover, because in countries like Egypt social policies are not well developed, or in some cases non-existent, disabled and frail older people have little alternative but to rely on their families for care and support. It is important to point out here that, although disabled activists argue that disabled people's problems should be addressed within a human rights framework I would suggest that in most cases the type of familial support described above, is given willingly and signifies a more positive aspect of inter-relations between disabled and non-disabled people that is not always reflected in the disability and policy literature.

Disability policy in Egypt

As in many countries traditional medical definitions are reflected in official statistics and survey data. However, what might be termed a more socially aware approach to the problems encountered by disabled people is clearly evident in welfare policies particularly with reference to employment issues.

In 1976 the Central Agency for Mobilisation and Statistics (CAPMAS) used a six-category 'disability' typology in its population Census to estimate the numbers of disabled people in Egypt. People were counted as disabled if they were: blind, had the use of only one eye, were 'deaf and dumb', had lost one or both upper limbs, lost one or both lower limbs, or were considered to have 'mild mental retardation'. Based on these criteria the data show that 111,324 people could be categorised as disabled out of a total population of 36,622,040; approximately three people per thousand (Fahmy 1995). Just over a decade later, a health profile of Egypt reported that the percentage of disabled people in the general population had risen to 1.52 per cent. One year later the Polio Institute declared the number of disabled people to be 11 per cent. In 1992, the *Pan Arab Project for Child*

Development suggested that disabled people numbered 1.54 per cent of the population (Shukrallah et al. 1997). The latest CAPMAS census of 1996 expanded its 'disability' categories to eleven. In addition to the above, these included people perceived as 'deaf', 'dumb', had polio, experienced 'total or partial paralysis', and/or 'other disabilities'. The survey concluded that 284,188 people out of a population of 59, 273,082, or 4.8 per thousand, should be classified as disabled (CAPMAS 1996). It is also worth noting that the CAPMAS data show that the number of disabled men far exceeds that for disabled women: 64.4 per cent and 35.6 per cent respectively. This might be due to the numerous conflicts that have plagued Arabic countries over recent years (Ahmed 1997) or that impairment amongst women is less likely to be reported (Hagrass 1998). It has also been suggested that only 20 per cent of the disabled population live in urban areas and that cities account for 80 per cent of disability related services (Nosseir 1989; El Banna 1989).

The discrepancies among estimates of the incidence of impairment may be attributed to several factors. First, the criteria upon which 'disability' may be reported are vague. Second, in most of these studies, the reporting of disability is to disabled people themselves or, in most cases, family members. Hence there is reliance on subjective understandings of what constitutes impairment or 'disability'. Finally, in each of these studies, the items pertaining to disability are usually considered of minor importance. This led to them being taken lightly or ignored (Fahmy 1995, 2000; Ahmed 1997; Shukrallah et al. 1997). As international estimates suggest that around 10 per cent of the population in most nation states may be considered 'disabled' these figures have only limited reliability (Fahmy 2000). What is certain is that the number of disabled people in Egypt is not small. Therefore, their rights should be ensured through the enactment of appropriate laws and policies.

Interestingly, since the 1950s several laws and policies concerning disabled people have been introduced in Egypt. The social welfare legislature of 1950 contained a specific chapter dealing with the 'rehabilitation of disabled persons' (Fahmy 1995; 2000). However, greater emphasis was placed on disability issues following the 1952 revolution when the Government issued several legislative measures intended to secure 'care' and security for disabled individuals. Among these were the: Labour Law, 91 (1959), Rehabilitation Law, 14 (1959), Social Welfare Law, 133 (1964) and the Health Insurance Law (1964) (Ministry of Insurance and Social Affairs 1987).

A number of points need to be considered when assessing the impact of these laws on Egyptian society. Significantly the Government Department responsible for issuing and implementing both the Labour and Rehabilitation Laws is the Ministry of Social Affairs and Manpower. Hence the responsibility for rehabilitation, training and employment is located in one government department. While there are potentially clear advantages to this approach in terms of internal communication amongst the staff concerned with various elements of policy implementation; communicating with other relevant ministries may be problematic. Further, following similar policies elsewhere in the 1950s (Lunt and Thornton 1994) the Labour Law of 1959 introduced a 2 per cent quota scheme for employers to ensure the recruitment of disabled workers to their workforce indicating Governmental recognition of the importance of employment in disabled people lives.

The Social Welfare Law 79 of 1975, and subsequent amendments, in particular, Law 25 (1977) and Law 92 (1980), are amongst those that deal specifically with disabled people's welfare rights. Their principal function is to ensure that people who acquire impairment through work related injuries or diseases receive appropriate compensation and pensions. However, payments and benefits are calculated solely on the basis of individualistic medical assessments. These assessments do not take into account the psycho-emotional consequences of the onset of disablement or the social circumstances of the individual concerned. Moreover, the Law of Civilian Employees 47 of 1978 and the Law of Public Sector Employees 48 of 1978 also include articles relating to the employment of disabled workers. These statutes were introduced to secure employment for disabled workers in state sponsored agencies and organisations. Priority is given to disabled war veterans, their children and family members if they are judged to be unfit for work.

During the 1970s the Egyptian Ministry of Social Affairs (MoSA) introduced the Rehabilitation Law 39 (1975), later amended under Law 49 (1982), in order to bring together disability policy under one statute. The new Law raised the employment quota for disabled workers, mentioned above, from 2 to 5 per cent. Whilst this may be seen as a step forward, it can also be argued that it reinforces the conventional notion that disabled people are somehow different from the rest of the community and, therefore, need 'special' provision. Even though the quota scheme ensures that there are some job opportunities for disabled workers, its application in practice is restrictive in that it tends to alienate disabled

workers from non-disabled colleagues, inhibits their ability to compete in the open job market and, consequentially, does not promote equal opportunities in the workplace.

Significantly, there is no reference to disability issues in other Egyptian legislation. Consequently there is a tendency for policy makers generally to ignore disability issues; they are viewed as a rehabilitation issue and someone else's problem. For example, the employment of disabled people is covered by the Rehabilitation Law 39, but not in the Employment Law 137 (1981), apart from a brief reference to the registration form that should be completed by employers who employ disabled people (Ministry of Manpower 1981:213).

This exclusion of disability issues from other policy initiatives can be explained with reference to the underlying assumptions upon which the Rehabilitation Law is based. For example a disabled person is defined as:

> any individual who became unable to depend on him/herself in performing his/her work or another [type of] and remains in it. His/her inability to do so is the result of physical, mental, sensory or congenital impairment.

Furthermore, rehabilitation is described as:

> presenting social, psychological, medical, educational, and professional assistance to all disabled persons and their families to enable them to overcome the negative consequences resulting from impairment (Law 39, 1975: 1).

It is clear that both definitions focus exclusively on the functional limitations of the individual and their assumed lower job performance and inability to function without professional support. In the same way as the academic definitions discussed in the first section of this paper, they present only an individualistic medical portrayal of disability. A major concern is that impairment is the sole cause of the problems associated with disability and once again, there is no reference whatsoever to environmental and cultural barriers. Furthermore, in the definition of rehabilitation, impairment is the problem and rehabilitative interventions are directed exclusively toward the needs of the individual and their family.

By continually re-enforcing the orthodox essentially negative views of disability and, by implication, people with impairments, the interpretations of both disability and rehabilitation in Egyptian law inadvertently perpetuate discriminatory attitudes and prejudice toward people with impairments. Furthermore, some sections of the disabled population are treated more favourably than others. For example, Article 3 specifies that

disabled citizens on a 'low income' are entitled to free rehabilitation. Those on higher incomes are not. It is worth noting that there have been no further amendments to these laws since the 1980s. As a consequence Egyptian disability policy is still encapsulated within a traditional individual, medical model of disability framework. The underlying assumption is that disabled people's experiences and life chances are determined exclusively by their impairment. At the societal level, the individualisation, medicalization and objectification of disabled people's lives remains intact. As a result the powerlessness that characterises the experience of many disabled people's lives goes unchallenged.

Conclusion

In this chapter I have endeavoured to show how the traditional individualistic medical or personal tragedy model of disability continues to dominate Egyptian disability legislation and policy. It has also been suggested that although cultural factors play an important role in social interactions between disabled and non-disabled people and, as a result, lay responses to the support of people with impairments are often less harsh than those suggested in some of the disability literature, this continued dominance has significant negative implications for disabled people's on-going struggle for human rights and equal treatment. This is especially worrying given the growing acknowledgement at the international level that disability is both a medical and social issue that warrants nothing less than an overtly socio-political response (see, for example, *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (UN 1993)).

In an effort to resolve this unfortunate situation it is therefore imperative that the international disability movement and their allies within the academic community continue to draw attention to the policy implications of both the medical and social models of disability and, in so doing, help influence national governments, such as that of Egypt, to re-formulate disability policy within a universally acceptable human rights framework.

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