

Disability Policy and Provision in Jordan: A critical perspective

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INTRODUCTION

This paper provides an outline of current disability provision, policy and legislation in Jordan. Reference is made to the emergence and development of these policies and services, especially the part played by western/international organisations in this process. Background information on Jordan, the current situation of disabled people and dominant social attitudes to disability is also presented by way of context. The findings are based on secondary literature, and on empirical data generated whilst working towards a Ph.D. on "The Economic Needs of Disabled People in Jordan".

SETTING THE SCENE

The historical development of the Jordanian state is inseparable from the flight of refugees from other countries in the region, including 800,000 Palestinians who fled to Jordan from conflict in the West Bank and from the Gulf War (Wilson 1991). By the early 1990s there were already 1.1 million refugees registered with the United Nations Refugees Work Agency (UNRWA) in Jordan. As a result, Jordan has become the focus of international attention and foreign aid

Also over the past few decades, Jordan has experienced its share of rapid socio-economic development and socio-economic crisis. The major economic crisis of the latter half of the 1980s resulted in a significant drop in the general standard of living (ESDP 1993). This was compounded by the return (due to the Gulf War) of 300,000 Jordanians in 1990 - economic migrants whose return meant not only a rise in the overall population (to over 4 million people), but also a marked reduction in national revenue in the form of lost remittances. The Gulf War also led to increases in water shortages, in unemployment (to 20%) and in the number of people under the poverty line (to 6.6%). The overall scene, therefore, is one of economic constraints for a growing number of Jordanians as well as Jordan's huge refugee population.

In Jordan, the Gulf War and ongoing conflict on the West Bank have also impacted on the number of disabled people in the country. There has been a rise in the number of people with conflict-related impairments (especially among the refugee community), while the capacity of government and localities to respond to the needs of disabled people is under strain (Acton 1983, UNICEF 1993, Turmusani & Sime 1994). There are, however, no accurate figures on the number of disabled people in Jordan (ESCWA 1994). If one assumes that at least 4% of the total population has impairment (see Coleridge 1993 and Helander 1993), this would suggest that there could be some 170,000 disabled people in Jordan. Evidence from a recent survey conducted by the Department of Statistics in 1991 states that 11% of families reported having a disabled family member. This would give a total of 66,000 families in Jordan with one or more disabled family members (UNICEF 1993, Zu'bi 1991). Of course, such statistics are open to question, not least since socio-cultural values are known to play a major role in determining who is identified (by self, family and others) as "disabled" and what is counted as an "impairment" (Johnson 1991). For example, the only nationwide survey to date on impairment in Jordan (conducted by the Queen Alia Fund) focused solely on the incidence of visible impairment (QAF 1979). It is only recently that impairments like speech difficulties and learning difficulties have been considered at all when defining who is and who is not a disabled person in Jordan.

Whilst it may not be possible to get an accurate count of the number of disabled people in Jordan, it is certainly possible to get a good understanding of the problems that many of them confront every day.

THE SITUATION OF DISABLED PEOPLE IN JORDAN

Recent research on disability in Jordan and empirical data gathered during fieldwork in 1996 all point to the serious disadvantages faced by disabled people in Jordan in relation to every area of life, including education, health, training and employment (Barghouthi and Al-Dean 1994, ESCWA 1994, Hinchcliffe 1994, Zomu't 1993).

The design of transport systems and public and religious buildings is such that they are inaccessible to many disabled people (Khatib 1994); while access to information is also greatly restricted (there is only one sign-language television programme for deaf people each week, and the range of reading materials for blind people is also very limited - see Hinchcliffe 1994).

The economic situation of disabled people in terms of employment and welfare support also leaves much to be desired. The Centre for Strategic Studies estimates that national unemployment among Jordanians could now be as high as 22-27% (CSS 1998). It is widely accepted that the rate of unemployment among disabled people in Jordan is even higher, and that disabled people are far more likely to live in poverty. Here, the absence of a welfare system and the absence of positive policies to promote the employment of disabled people serve to compound these existing inequalities. Barriers to employment are especially severe for people with a label of "mental retardation", people who have cerebral palsy and deaf people (Khatib 1989).

There is a severe shortage of specialised centres, personnel, funds and facilities to support disabled people - especially in rural areas. There is also practically no support from governmental and non-governmental bodies to disabled people who wish to live independently in the community, although the Queen Alia Fund has started to change this with a small programme to support disabled people who live in their own home through providing adaptations such as appropriate toilets and a ramp (QAF 1994). Generally, however, what little assistance there is takes the form of residential accommodation.

This situation is far from unique to Jordan. Similar conclusions have been drawn in relation to disabled people worldwide ... both in the west (see Barnes 1991, Dalley 1991, Oliver 1990 for example) and in developing countries (see Coleridge 1993, Helander 1993 and contributions to Zinkin & McConachie 1995). The overall picture is one of inadequate services, socio-economic structures that exclude disabled people, and a lack of access and equal opportunity. It is also one of negative social attitudes.

SOCIO-CULTURAL ATTITUDES TO DISABILITY: AN OVERVIEW

An analysis of dominant socio-cultural attitudes to disabled people in Jordan throws up some insightful, even contradictory, evidence. On the one hand, it is possible to identify an Islamic version of the philosophy of equal rights for people with impairments. For example, there is an episode in the Holy Qur'an which tells of God reprimanding his Prophet when he turned his back on a blind man who asked for advice and knowledge (Ali 1994: Surah Abasah verses 1-5, also Miles 1995). On this basis, it might be argued that God wishes all members of Islamic society to receive equal treatment, irrespective of impairment. On the other hand, however, there are several verses in the Qur'an and Hadith that reveal a much less accommodating, even discriminatory, attitude to disabled

people (Turmusani 1998). Unfortunately, evidence collected during fieldwork and from other sources within Jordan would seem to suggest that negative rather than positive attitudes to impairment are the more dominant - especially in rural areas.

Islam is the dominant faith for more than 92% of the population. A core message of Islam is that anything that occurs and everything that exists in the world can be attributed to the will of God. Accordingly, impairment may be explained as an act of God, designed to test the faith of individuals and their capacity to accept that fate with gratitude and patience. This perception of disability as a test of the faith and as God's will plays a major part in shaping attitudes towards disabled people.

There is also evidence that Arab societies (including Jordan) have tended to treat disabled people as people with no prospects and no potential (Khatib 1989), and have viewed impairment as something shameful and as an ordeal to be endured by the family. Thus, for fear that knowledge of an impairment within the family might incur difficulties in securing marriages, many families have denied the existence of a disabled family member (see also Coleridge 1993). Guilt and pity may also prompt some parents to "hide" their disabled children, with the result that access to appropriate services (where they exist) is even further restricted.

Disabled people constitute, and/or are perceived to constitute, an inevitable and significant drain on family resources and a potential source of damage to family status. Such attitudes have also been evident in the media: until recently, the media in Jordan has portrayed disabled people as passive and dependent, thereby perpetuating a negative image (Khatib 1994).

There are some signs of change. Public attitudes towards disabled people in Jordan seem to have improved over time, at least towards some sections of the disabled population. The changes are particularly apparent in relation to people with sensory and less severe physical impairments (rather than people with "mental retardation"), and in relation to men rather than women (see Quryouti 1984 and Florian & Katz 1983 on the status of people labelled as "mentally retarded").

Although the position of women in Jordan has improved in comparison to other Islamic countries, women still occupy a different status to men. In some parts of the country, women are considered to be awra (i.e. women's faces and bodies

must not be exposed to public view) and are not allowed freedom to choose a husband, express an opinion or live on their own. The situation of disabled women, especially those who are labelled as "mentally retarded", is even worse since disabled women are often viewed as an endless burden on their families - both morally and financially. In southern Lebanon for instance, it has been reported that a disabled girl was left to die following an Israeli military offensive on her village and family home. The father was reported to say that he preferred to save the family cow rather than his disabled daughter because the cow was more useful (Habib 1998). Generally, where a disabled woman is the focus of family concern, this is less out of concern for her well-being, than for the protection of family honour.

In summary, negative attitudes towards disabled people and discrimination against them have a long history in Jordan.

DISABILITY-RELATED PROVISION IN JORDAN

Institution-based and community-based (see Coleridge 1993) services are provided by and/or funded by professionals working for international and national non-governmental organisations, government and the private sector. These include: early detection services, special education services, rehabilitation services, vocational training services, sheltered workshop services, employment schemes and community-based rehabilitation programmes. There are 72 centres for disabled people which are run by NGO, government and private sectors; and they provide services to around 7,000 disabled people (less than 2% of the total population of disabled people). In this paper, I focus on services related to employment and community-based rehabilitation. All the statistics were gathered during fieldwork in late 1996.

Employment schemes and services

The importance of employment for disabled people is a key issue (Barnes 1991, DAA 1995). Often, self-employment is regarded as preferable to sheltered employment, while open employment is the most favoured option. However, the barriers to open employment in Jordan are significant. Several schemes have been set up with a view to increase the number of disabled people in work. Currently, two government bodies in Jordan are responsible for employment policy and creation of economic opportunities for disabled people: Ministry of Labour and the Vocational Training Corporation. Other organisations, especially NGOs, are also involved.

- Vocational training services are conceptualised in Jordan as an integral part of special education, irrespective of market demands or employment opportunities. The services offer low quality and limited skill development, often with inappropriate supervision. Training- opportunities are very limited: only 276 disabled people - all between 14 and 24 years old - were in receipt of this service in 1996 (that is, less than 4% of the total population of disabled people who receive services). Of the 9 vocational training units in the country, 3 target "mentally retarded" people; 2 target deaf people; 2 target people with a physical impairment; and only 1 unit is open to people with different impairments. Most of the trainees are men. All of the centres are located in cities.
- There are 4 sheltered workshops in the country and, again, they are all located in big cities. They employ around 83 people with mild impairments - people who have graduated from vocational training programmes. According to Hinchcliffe (1994), the working conditions in these sheltered workshops are poor. The workshops are run by the voluntary and international non-governmental sectors, not by the state. Even though sheltered workshops are considered by many to be an unfavourable option (ILO 1989), there are still very long waiting lists of potential employees.
- The Friendship Society for the Blind started the first scheme to set up self-employment projects for blind men, primarily in Amman. In the 1980s, the National Aid Fund started to provide micro-credit loans for husbandry projects, and support to purchase aids and equipment. This support was also open to disabled people and, in contrast to other schemes, operated in rural areas. In 1992, the General Union of Voluntary Societies and the United Nations Development Programme established a self-employment scheme targeted at disabled people. Unfortunately, disabled people were not involved in the design and delivery of this project - this was reflected in the low attendance record of disabled people (GUVS 1994).
- In 1994, the National Council for the Welfare of Disabled People established a new department with responsibility for promoting the open employment of disabled people in public and private sectors. It is reported that about 150 disabled people have been employed in the private sector, although this is mostly a result of personal contacts rather than legal incentive or enforcement (NCWDP 1994).

Community-based rehabilitation schemes and services

Community-based Rehabilitation (CBR) has been put forward as one way to increase the availability of services to disabled people in developing countries (see Coleridge 1993, Khatib 1994, Daoud 1991, Andrew 1991). The key principals of CBR are low-cost and simple technology, the use of local resources, and community participation (Twible & Henley 1993, Ingstad 1995, Helander 1993). In Jordan, the eight CBR programmes - serving a total of 500 people - which are currently under way or in the planning stages have been spearheaded and funded by international agencies and organisations. Where local NGOs are involved, their role has been limited to delivery rather than design and management of services.

- In the early 1980s, the first CBR project in Jordan was set up and run by the United Nations Refugee and Work Agency (UNRWA) in a refugee camp. Nowadays, UNRWA runs six CBR programmes - all in refugee camps.
- In 1991, UNICEF funded a pilot CBR project in 13 villages of Mafraq district, following recommendations made at the Jordanian/Swedish Medical Association conference in Amman (QAF 1994). The only part of the original project that is still active is a mobile clinic unit, which is administered by a local NGO (with funding from UNICEF). The mobile clinic provides medical rehabilitation services to some parts of Mafraq district.
- In 1995, the Holy Land Institute for the Deaf started a CBR project for people with hearing impairments in Salt District in central Jordan (HLID 1994).

Other Schemes and Services

- There is no welfare system in Jordan, although the National Aid Fund has some responsibility (more on paper than in reality, it seems) to provide support for disabled people to provide grants for individual rehabilitation purposes.
- There are no organisations controlled by disabled people, although it is interesting to note that Deaf people in Jordan have recently started to set up their own social clubs (Hinchcliffe 1994).
- There is a Jordanian Federation for Handicapped Sports, but it is the only cross-impairment organisation related to sports and recreation

opportunities for disabled people. It is based in Amman and has very limited resources and capacity.

- A few workshops produce disability aids and equipment (e.g. wheelchairs).

All of this looks bleak. The good news is that - on paper - things should get better as a result of recent legislation which sets out the facilities and services that disabled people and their families should start to expect to get. These are discussed shortly. Before that, it is important to consider some of the main problems that have impacted on the provision of services, their appropriateness and their effectiveness.

SOME LIMITATIONS AND CONSTRAINTS

Several of the services exist more in name than in reality. For example, the National Aid Fund has a remit to provide financial support to people in poverty, including disabled people. Support might include a micro-credit loan or a grant towards meeting rehabilitation needs. However, access to this support depends on a number of conditions and criteria, including politically-related allocation priorities. Procedures are long and complex. The potential geographical distribution is very wide.

Advocacy and self-organisation of disabled people exists in only limited form. Despite the fact that the right of disabled people to participate in decision-making relating to their life is guaranteed by recent legislation (see below), the reality falls far short of the idea. The government seems to prefer professionally-run services for disabled people; and where there have been attempts to form organisations of disabled people or to set up consultations, these have failed. At the time of data collection in late 1996, there was only one parents' society - which was inactive - and a failed attempt by some disabled people to set up their own organisation (the failure seems to have arisen from a leadership conflict among the membership).

The lack of a mobilised "voice" of disabled people in local areas and nationwide, combined with the preference of those in government, voluntary and private sectors to deploy professionals rather than adopt a community-based approach which involves disabled people, has had a negative impact on the appropriateness of services provided. One example is the inappropriate voluntary sector scheme to promote self-employment among disabled people: the buildings used were inaccessible with no appropriate facilities, and disabled

people were not consulted as to the type of employment they wanted - so attendance was very low (see Turmusani & Sime 1994). Another related issue lies in the failure of those running vocational training schemes to consider local market demands, with the result that training provided does not equip individuals with the skills they need to thrive in the local economic and competitive labour market.

The government's preference for professionals is reflected in a range of schemes to provide skills and training to those professionals who already work with disabled people, in order to enable them do their job better - for example, through supporting professionals to gain postgraduate academic qualifications in special education and through the provision of in-service training and local or overseas exchanges. A major problem, however, is how to retain those who have been trained - since many higher-level professionals turn to employment in the private sector or overseas rather than receive the lower salaries on offer in government and voluntary sector work in Jordan. A more promising approach - although it is firmly based in a "medical model" of disability, is the creation of an Occupational Therapy College (a new joint-project between GUVS and Royal Medical Services, with funding from the British Government). This is one of the leading professional institutions in the country; and there is a high demand for graduates both within local communities and further afield.

The severe shortage of appropriate services, personnel, funds and facilities in disability-related work in Jordan (see above) means that the few disability projects that do exist operate under significant constraints. They have to learn to do a lot of work with very few resources. This is compounded by an apparent lack of planning, co-ordination and co-operation between the agencies that are involved in disability and rehabilitation programmes in Jordan, which further restricts the potential impact of these services to benefit disabled people (Hinchcliffe 1994). This lack of co-ordination results in the unnecessary duplication of services and an inefficient use of limited resources (WPACDP 1983). It is more than likely that low capacity, lack of planning and lack of consultation, and over-stretching capacities in terms of geographical spread were the root causes of programme failure in the CBR project in Mafraq district (see above).

THE DEVELOPMENT OF DISABILITY POLICIES IN JORDAN

A medical model of disability, exemplified by many professional practices, western NGOs and international agencies, has penetrated the local culture and

affected attitudes towards disability in Jordan. Clearly, this is not to say that negative attitudes towards impairment and disability have only emerged since the 1960s (when international agencies and organisations became active in disability in Jordan)...the information on "traditional" attitudes outlined in the previous section is proof enough of that. It is, however, to argue that the ways of working and the scope of projects implemented by western organisations have influenced the attitudes and shaped the responses of the Jordanian government, voluntary and private sector, as well as families and individuals.

In Jordan, as in many countries, rehabilitation services for disabled people have been initiated in the wake of war and conflict. The increased incidence of conflict-related impairment, and the reduced capacity to meet the needs of disabled people, have often been the catalyst for more state and, significantly, international involvement in the lives of disabled people (see Ingstad 1995). In Jordan, disability-related provision began in the 1960s and was led by foreign NGOs which provided institutional (residential) care for severely deaf and "mentally retarded" people. In the 1970s, government and voluntary organisations followed suit and began to get involved in western-style institutional provision for "mentally retarded" people. In time, western-style institutions which specialised in institutional care, special education, vocational training, and rehabilitation began to spread throughout Jordan (Khatib 1994). No matter how well intentioned these international and local initiatives might have been, there is little doubt that the result of western influence has been a view that equates "institutions" and "special" with "disability provision", and which thereby promotes the marginalisation of disabled people in society, and their exclusion from "mainstream" services and provision.

A further legacy of western influence is the degree to which disabled people and related services have been seen as the tasks of non-governmental organisations and the voluntary sector, rather than the responsibility of the government. The existence of comprehensively funded services for disabled people has encouraged reliance on these (mostly international) NGOs and agencies, and therefore discouraged the development of formal state-run and state-funded services. None of this is to deny the important contributions that have resulted from western and international involvement in disability (e.g. rehabilitation, care services, training) - it is simply to point out that these contributions have been at a cost.

The nature of service provision has impacted on family responses to disabled people. There is now a stronger view that disabled people are no longer a family

responsibility alone: communities and government also have some responsibility to meet the needs of disabled people. This view has certainly been influenced by western involvement in establishing residential centres for disabled people, thereby taking over what had previously been the sole responsibility of the family (see Mallory et al 1993 on the impact of western, especially colonial, influence on attitudes towards and provision for disabled people in developing countries). From my research and experience, it seems that poorer families may now be more inclined to send severely disabled family members to residential institutions out of a belief that such western-style and (often) western-funded institutions provide better services than can be offered by the family.

The level of international interest has not reduced. Indeed, it received a boost in the International Year of Disabled Persons (1981) and the subsequent United Nations Decade of Disabled People (UN 1994). 1981 was also, however, a turning point in Jordan in terms of the government's agenda for disabled people and public awareness of disability. It can be argued that, since then, state and voluntary sectors within Jordan have taken steps to provide disabled people with more appropriate services, with a view to enabling them to contribute to society and also to meet Islamic obligations in providing equal opportunities regardless of someone's mental, physical, or economic condition. But there is a very long way to go, since services are still provided to less than 2% of the total population of disabled people in Jordan (Khatib 1994, UNICEF 1993).

Finally, it should be noted that the Monarchy of Jordan has played an important role in supporting disability policies and legislation. The involvement of members of the Royal Family in public life, especially in disability issues, has speeded up the introduction of disability legislation and, through organisations like the Queen Alia Fund and the Al-Hussein Society for Physical Handicap, has provided additional services. Here again, however, the influence of international agencies is clear.

It is clear that both foreign and indigenous forces have contributed to the emergence and development of non-family responses to disability. The interplay of these forces has resulted in a complex set of policies, programmes and practices that reflect both local values and values that originated in very different sociocultural contexts. I would argue that a medical approach to disability has been paramount, and that this has largely been introduced through western involvement in disability in Jordan. What is required now is a transformation of this approach to what has been called a social model of

disability, which focuses on social solutions rather than individual solutions (see Crow 1996, Barton & Oliver 1997, Barnes 1991 & 1996, Oliver 1990 & 1996, Lunt & Thornton 1994, and Turmusani 1999 among others).

LEGISLATION AND DISABILITY IN JORDAN

The International Year of Disabled Persons was also the first time that thought was given to legislation as a means of improving the situation of disabled people in Jordan. Since 1981, many attempts have been made by parents and activists who work in western NGOs to formulate appropriate legislation under the supervision of the Ministry of Social Development, and with the support of Their Royal Highnesses Ra'ed Ibn Zaid and Firas Ibn Ra'ed. Eight years later, in 1989, a Provisional Law for the Welfare of Disabled People (No.34/1989) was passed. Then, in 1993, the provisional bill was passed and Law No.12/1993 for the Welfare of Disabled People came into existence.

The mission statement of this Law is to ensure the rights of disabled people for services and provision which will promote their integration into society and affirm their rights:

This law affirms the right of disabled persons to education, training, employment, rehabilitation, medical treatment, sports and recreation, transport, aids and equipment and materials, support services and participation in decision making as far as the resources allow. This law establishes a body called the National Council for the Affairs of Disabled Persons to implement the law (see NCWDP 1993).

In order to make these rights a reality, there is a strong need for all relevant parties (including government, NGOs and the private sector) to co-operate and co-ordinate their efforts; to enforce implementation of the law; to involve society and raise awareness of disability and the law, and so forth.

The definition of a disabled person is:

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 inhibit him/her short of fulfilling his/her normal daily requirement in circumstances similar to those of able-bodied persons (NCWDP 1993).

Some impairments, such as dyslexia, are not included.

Hinchcliffe (1994) has criticised this law on the basis that many of the "rights" established depend on the discretion of the Minister of Social Development. Also, representatives of disabled people are appointed by the Minister rather than by other disabled people or groups they might represent. The high turnover of members of the various government ministries and organisations, who have been appointed to debate the implementation of the law, will lead to a low-level of commitment and consistency in decision-making and in enforcing the law. Finally, the law is clearly based on a "welfare" rather than a "rights" perspective, thereby setting the scene for continued dependency on others, especially on welfare and disability professionals (Turmusani 1998).

It is arguable that nothing will change until serious mechanisms (and resourced mechanisms) are in place to implement rights such as the right to employment. The right for employment of disabled people in Jordan is guaranteed by the new law, and there are several sections of the law which discuss the opportunities and support that disabled people should expect to access. However, evidence from fieldwork shows that disabled people's participation in the economy remains very limited and the majority of disabled people - including those who are well-trained or qualified - are unemployed or employed in low-skilled, low-paid work. The preference for employing non-disabled people remains strong. The situation is little different whether in the public or the private sector.

CONCLUSION

There is a growing awareness of the substantial contribution disabled people make, and can make, to their local communities and society in general. All too often, development plans bypass disabled people and, when they do take account of disability, tend to treat disabled people as "separate" and "special". I have argued that this is the case in Jordan.

In Jordan, disabled people are marginalised and experience socio-economic disadvantage as well as negative socio-cultural attitudes. Existing disability-related provision, policies and legislation are inadequate, poorly-resourced, more apparent on paper than in reality, and underpinned by the view that institutional, special and medical provision, run by professionals with little involvement of disabled people, constitutes the most appropriate form of disability provision. Even when discussion turns to employment schemes, it is clear that most of the limited opportunities that exist are in low-level jobs, set

apart from other employees. Moreover, the increase in service provision since the 1960s (e.g. residential centres, employment schemes, CBR outreach) is minute compared to the needs of 98% of disabled children and adults who do not receive support in the 1990s. The distribution of priorities and approaches to disability in Jordan must change if Jordanian state and society are ever to meet these present demands (Turmusani & Sime 1994). In my view, existing policies, provision and legislation will only contribute to disabled people's empowerment if the following factors are in place and prioritised:

- Support to disabled people to promote their self-organisation and self-advocacy.
- Increased access to financial and other resources - for individual disabled people, groups of disabled people, and also for service providers.
- Promotion of a social model of disability among disabled people, society in general, service providers in government, voluntary and private sectors and, of course, among those western NGOs and international agencies that are still working and will continue to work with disabled people in Jordan.

With these factors in place, and with co-ordination and collaboration, disability policy and provision in Jordan could be greatly improved.

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