

# THE DISABLED IN THE FAMILY

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In an Expert Group Meeting on "Social Barriers to the Integration of Disabled Persons into Community Life" (convened by the United Nations Department of Economical and Social Affairs at Geneva in July 1976), the participants exchanged views on a wide range of problems and obstacles known to impede the integration process.

In some traditional African societies for example, disability was viewed as a disgrace to the whole family, and as a result, handicapped members of the family might be hidden from outsiders; it was also often considered undesirable for disabled persons to have marital and sexual relationships.

In many Asian countries, the attitude of the community towards disability was fatalistic, with established discriminatory rules and injunctions against handicapped people. In Latin American countries, some schools still rejected disabled children and the majority of affected persons in rural areas could not benefit from the rehabilitation services available in urban areas; the most important social barriers to integration were the lack of community education, the rejection or the overprotection by the family and the marked dependence of disabled persons on others. In Third World communities, prevalent conditions of illiteracy and superstition affect disabled persons by making them feel inferior and, in some cases, even unwilling to be integrated into the community.

In general, able-bodied persons harbor prejudice against the handicapped because they believe that the disabled fundamentally differ from them due to a biological inferiority, which they presume to overshadow all potential abilities and skills. Because of this presumed infirmity, a wide range of occupations and social options are denied to the handicapped, who are often also considered to be less intelligent, less logical, and less able to make the "right" decisions when it comes to determining their own lives.

And where do we, in the Arab World, stand with respect to the integration of the disabled in community life? In this article I will focus on the disabled child, its psycho-social position within its family, the attitudes that surround it, the available educational opportunities, and the child's future

prospects as a grown-up member of society.

Unfortunately, most of what we saw described in 1976 still applies in 1997. Let us not, however, start off with a negative view and let us pinpoint instead the many positive achievements that have been implemented in the Arab World up to date. In general, over the past decade, governmental agencies and the private sector in several regions of the Arab world have given much attention to the problems of disability. With respect to mental disability, for example, great efforts have been made in Saudi Arabia, Kuwait, Oman, Qatar, Bahrain, Jordan, Algeria, Mauritania, Lebanon, Egypt, and Morocco to establish the bases for the vocational training of the mentally disabled, to ensure their employment in the private sector, and to provide high-caliber training in the fields of rehabilitation and special education.

In Egypt, blind children are given the opportunity of scolarization at the pre-school level; special educational institutions exist to handle visually-impaired children from a very early age. Moreover, universities in Egypt are equipped with Braille-systems and auditory libraries to facilitate the integration of blind students in university life.

In Kuwait, the private sector has been very efficiently active in serving people with disabilities. The quality of care given to multi-handicapped children and youth is quite impressive and much money is invested in the professional training of the staff. Physically disabled children as well as adults receive comprehensive services in an ultra-modern and highly-equipped center founded by the Kuwaiti Government in the early nineties. Kuwait is also considered a pioneer in the Arab world for having created a special resource center exclusively for children with learning disabilities.

In Lebanon, after years of bloodshed and destruction, the Government created in 1992 a Ministry to handle all issues related to disability, which gave thousands of people cause to hope for a brighter educational and vocational future and for ultimate integration in the community.

Yet, in spite of these very important achievements and the significant development in the quantity and quality of care services that disabled people can receive, a major problem without apparent solution remains: the community - at - large still lacks

awareness with respect to issues of disability, which entails faulty interpretations of and misconceptions about the status and the needs of the disabled person. This is mostly due to the fact that developing countries have limited economic and socio-cultural means and must attend to a short-list of priorities, namely poverty, ignorance, and physical health. These are, by themselves, cultural disabilities that do require radical emergency treatment. However, what societies fail to understand is that disability is not simply a marginal issue to be treated after and separately from the supposedly more urgent problems cited. The disability issue is indeed at the very core of these problems, for poverty (leading to undernourishment during pregnancy and in the first years of life, absence of educational opportunities to the child, *etc.*) as well as ignorance (consumption of the wrong medication during pregnancy, neglect of certain accidents and traumas during pregnancy, deliveries performed in most unsuitable conditions, *etc.*) and disease lead to a high occurrence of disability in any given society.

In the last decade, and especially so in Lebanon, outstanding efforts have attempted to promote social understanding and acceptance of disability via the media (television and radio, as well as congresses and seminars in almost all Lebanese regions). These efforts culminated in the famous Peace March from South to North Lebanon in October 1991, in which thousands of disabled people, their families, and friends participated.

And yet we see that, in spite of all these efforts, society continues to stigmatize the disabled person. Let us start from the very beginning. A disabled child is born into a family. First he/she is going to be confronted with parental feelings of guilt and fear. This initial confrontation is of crucial importance because it could lead to a very deep wound in the relationship of the child with its environment. The guilt feeling is very often found in parents who ponder the role of heredity, for, as we know, heredity plays an important role in the formation of the fetus. However, parents ought to remember that, although fetal formation may be hereditary, the child's development is not, and that their job is to try and give a value to their child, far removed from what he/she inherited biologically. Parents should be able to look at their disabled child as a source of power, regardless of his/her physical appearance, and they should realize the importance of his/her belonging to the family.

However, this is not what happens in reality. In most cases, the almost universal expectation of a "normal" child leads parents to reject the disabled child. This rejection will impede his/her social and psychological development, and hence the process of integra-

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tion. In our societies, which still are characterized by the extended family-type, the child is going to face a wide range of attitudes coming from a wide range of people (including family members whose interference is inevitable), and which represent a mixture of ignorance, fear, overconcern, support, overprotection, or else neglect, mistreatment, and even abuse.

The social stigmatization of disability in general, and the spread of this stigma to close relatives (blood relatives and spouses) in particular, constitutes a significant barrier to the familial integration of its disabled member. In some families, close relatives may even want to dissociate themselves from the stigmatized person and therefore reject him/her altogether. Moreover, some direct institutional discriminatory practices adversely affect the integration of disabled persons into the family, such as legislation that prohibits them from marrying and bearing children or that accepts some disabilities (mental illness in particular) as grounds for divorce.

The next problem that parents of disabled children have to face is the education (or "cure") of their child. What to do? Where to go? Whom to refer to? Only a minority of parents (usually the well-educated, well-informed, well-connected, and financially stable) decide to take initiative, knock on doors, and ask, sometimes aggressively, for what is a basic right for their child: a proper education. And it is thanks to those "aggressive parents" that, since the mid-fifties, most of the educational facilities and special-care institutions for disabled children were created.

The majority of parents remains passive, or rather utterly helpless. Not knowing where to go, not even aware of the availability of educational facilities, they keep the child at home, protect and pamper him/her, against a background colored with a fatalistic resignation to their tragic destiny; but by doing so, they are preventing the child from acquiring the skills he/she will need for proper rehabilitation and social integration. They are keeping the child forever under their control - in some cases, at their mercy - depriving him/her of the most basic right of a human being: the right of freedom. Of course, the above description fits the situation in rural areas better than in urban ones. In almost all Arab countries, most of the specialized schools that offer services for the disabled are clustered in the cities, often mainly in the capital, whereas the remote regions and villages remain deprived of such services.

Even in the cities, very few efforts at integration take place. Disabled children are still segregated in schools and training institutions, which prevents them from mixing with other children. Till today, our

schools are not equipped with the appliances and technical means needed to help disabled children and youth take part in the educational process; buildings are inaccessible and prevent them from using ordinary school facilities. Moreover, financial resources to fund certain educational programs (for example, special remedial classes within the ordinary school) are inadequate, as are the required manpower and the special equipment for the implementation of such programs.

Going back to the initial point of our discussion, namely the disabled child in his/her family, can we end on a positive note after this more or less bitter panoramic presentation of facts? What has been achieved in the Arab world as far as disability is concerned is very impressive, considering the many obstacles. We believe, however, that the major task facing us in this part of the world is to fight public ignorance and the many misconceptions it entails. No, a disabled person is not to be pitied. No, a disabled person is not contagious. No, a disabled person is not inferior to us. No, institutions for the disabled are not charity and welfare organizations. And this complex task starts at home, because there lies the essence of the problem: the parents of the disabled child should be able to gradually overcome their feelings of guilt and fear; to do so, they should realize that their child is a worthy member of the family just as his/her siblings. Such an attitude would positively affect not only the disabled child throughout his/her development but also the other members of the family. Moreover, parents should realize that they must involve the siblings in this integration process and rely on their cooperation in his/her education. The role of the mother is of crucial importance, because she more than anyone else in the family, is going to head this long battle against social inertia, indifference, depreciation, and rejection. Upon this battle depends the future of her child; the mother is the one who will wear an iron façade in the midst of hostility and discouragement, and who must communicate to the other members of her family her tenacity, her intransigence, her dynamism to continue the battle.

Through this familial network of joint efforts, the siblings will get to accept their disabled brother or sister, understand his/her condition, and respect his/her needs. Only then will the disabled person be adequately and strongly equipped to face the world outside the boundaries of the family and to fight the obstacles that he/she will surely encounter.

We are very much convinced that if the integration of the disabled child does not start at home on solid grounds, it will never reach the schools, the community, and society in general.