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# ECONOMIC AND SOCIAL COMMISSION FOR WESTERN ASIA

# PROCEEDINGS OF ESCWA REGIONAL SEMINAR ON THE ROLE OF THE FAMILY IN INTEGRATING DISABLED WOMEN INTO SOCIETY

## 16-18 OCTOBER 1994
## AMMAN

95-0491

**UNITED NATIONS**

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## EXPLANATORY NOTES

The following symbols are used in the tables throughout this study:

Two dots (..) indicate that the data are not available or are not separately reported.

An em dash (--) indicates that the amount is nil or negligible.

A hyphen (-) indicates that the item is not applicable.

The opinions, figures and estimates set forth in this paper are the responsibility of the author, and should not necessarily be considered as reflecting the views or carrying the endorsement of the United Nations.

Bibliographical and other references have, wherever possible, been verified.

# PART ONE

# FINAL REPORT*

## INTRODUCTION

1. In its resolution 31/123 of 16 December 1976, the General Assembly proclaimed 1981 the International Year of Disabled Persons (IYDP). This marked one of the United Nations most successful international events. It was observed in all countries and generated worldwide awareness of the rights, capabilities and needs of disabled persons. For disabled persons themselves, it was a milestone in the long history of the struggle against discrimination and for equal rights. One important outcome of the IYDP was the World Programme of Action concerning Disabled Persons, which was adopted by the General Assembly in its resolution 37/52 of 3 December 1982 and published by the United Nations in 1983.[1] The World Programme of Action is based on the principles of human rights, full participation, self-determination, integration into society and equalization of opportunities. It contains a set of guidelines for national, regional and international action. It represents a joint effort of Governments, United Nations agencies and non-governmental organizations (NGOs) to gain universal commitment to recognize the rights of disabled persons and to provide the services and opportunities for their full participation in society.

2. In adopting its resolution 37/53 of 3 December 1982 on implementation of the World Programme of Action concerning Disabled Persons, the General Assembly proclaimed the period 1983-1992 the United Nations Decade of Disabled Persons. The Decade provided a time-frame for Governments to intensify their efforts to improve the living conditions of disabled citizens. It was recommended that monitoring and evaluation be carried out, at periodic intervals, at international and regional levels, as well as at the national level, in order to assess the situation of disabled persons and to measure development.

3. At the international level, the Global Meeting of Experts to Review the Implementation of the World Programme of Action concerning Disabled Persons at the Mid-Point of the United Nations Decade of Disabled Persons was convened by the United Nations Office at Vienna. The Meeting, which was held at Stockholm from 17 to 22 August 1987, recognized that the opportunities offered by the Decade of Disabled Persons to stimulate implementation of the World Programme of Action had not been fully exploited and that insufficient progress had been made throughout the world.

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* This report was originally issued as E/ESCWA/SD/1994/WG.1/8.

[1] *World Programme of Action concerning Disabled Persons* (United Nations, New York, 1983).

4. Furthermore, the Expert Group Meeting on Alternative Ways to Mark the End of the United Nations Decade of Disabled Persons, held at Järvenpää, Finland, in May 1990, agreed that issues and concepts pertaining to the equalization of opportunities for disabled persons were of fundamental importance and therefore should be given priority in the formulation of a long-term strategy to the year 2000 and beyond. The theme of such a strategy, endorsed by the General Assembly in its resolution 45/91 of 14 December 1990, is "A Society for All: From Awareness to Action".

5. In 1991, the General Assembly invited Member States and organizations of the United Nations system to prepare the preliminary outline of a long-term strategy to the year 2000 and beyond. In accordance with the recommendations of Economic and Social Council resolution 1991/9 on the United Nations Decade of Disabled Persons, an expert group meeting was held in conjunction with the conference entitled "Independence 1992" organized by the British Columbia Pavilion Corporation in collaboration with Disabled People's International and other non-governmental organizations, with the primary objective of drawing up a global long-term strategy to further the implementation of the World Programme of Action to the year 2000 and beyond. The Meeting proposed several practical recommendations in areas such as legislation, community-based rehabilitation (CBR), independent living, human rights, economic independence and the creation of an effective mechanism to coordinate and monitor activities from 1992 onwards.

6. At the regional level, in November 1989, ESCWA organized the Conference on the Capabilities and Needs of Disabled Persons in the ESCWA Region, held in Amman from 20 to 28 November 1989 and attended by some 200 Arab and international experts, 40 of whom were disabled persons. The Conference put forward 55 concrete recommendations including recommendations to promote public awareness of the capabilities of disabled persons and the role of the mass media, disability legislation and NGO coordination.

7. The Cultural Event for Disabled Persons in the ESCWA Region: an Event to Mark the End of the United Nations Decade of Disabled Persons in the ESCWA Region, which took place in Amman on 17 and 18 October 1992, was an immediate follow-up activity to the 1989 ESCWA Conference, with special emphasis on promoting public awareness of the capabilities and creativity of disabled persons. A series of cultural events organized by disabled artists and NGOs took place, with the aim of marking the end of the Decade in a way celebrating Arab culture. The Event was also timely, as it provided a forum for disabled artists and participants to demonstrate their capabilities and creativity within the framework of the global end-of-Decade promotional campaign. The substantive sessions of the Event were aimed at evaluating the implementation of the World Programme of Action at the end of the Decade in the ESCWA region and at formulating a regional long-term strategy, comprising a new set of action-oriented objectives to enhance the progress already attained during the Decade. The sessions were also devised to raise the awareness of regional mass media

professionals regarding their role and responsibilities towards disabled persons, and to strengthen coordination among NGOs of disabled persons. Throughout the deliberations, special attention was given to the full participation of disabled experts. The chairperson of the plenary session was a blind expert. Jordanian sign language interpretation was made available in the plenary session to ensure the participation of deaf persons in the discussions. Selected background documents were available on tape for blind experts, and the Conference venue was selected in order to ensure accessibility by physically disabled persons to its facilities.

8. During the Cultural Event, it was agreed that disabled women and children should be given special attention, and the role of the family (particularly the mother) and CBR approach were emphasized. Concurrently, ESCWA published a series of substantive papers on social issues related to Arab women and the Arab family. These publications served as background papers to the agenda items of this Seminar, and the outcome of this Seminar will be an input to the planned ESCWA regional preparatory meeting on the International Year of the Family. Outputs from this Seminar, including the background papers, recommendations and statements will be incorporated in the Regional Plan of Action for the World Conference on Women to be held in Beijing in 1995.

9. The ESCWA secretariat hopes that the wide dissemination of this final report of the Event—which is available in English and Arabic and in the form of synthesized voice and large print for visually impaired persons—will contribute to the strengthening of regional activities in the field of disability and will help policy makers, researchers, caretakers and disabled individuals themselves to identify areas of interest for future action.

## I. ORGANIZATION OF THE SEMINAR

### A. ORGANIZATION OF WORK

10. The Seminar included the following major components:

(a) Substantive presentations and discussions on women and disability issues:

(i) A plenary session (in the form of substantive presentations and discussions) on the extent and nature of the problems of disabled women and children in the ESCWA region, with particular emphasis on their socio-economic characteristics and the level of their social integration (social marginalization); childhood disability and the role of the family (particularly mothers) in terms of prevention, early intervention and rehabilitation; and the role of grass-roots NGOs (particularly women's NGOs) in community-based rehabilitation (CBR);

(ii) The United Nations Inter-Agency Task Force Meeting on Disability in the ESCWA Region;

(iii) Working group discussions to develop the guidelines for promoting social integration of disabled women in the ESCWA region;

(b) A series of cultural events by disabled persons and field activities:

(i) Exhibit of artistic work by disabled women, showing their capabilities;

(ii) Charity bazaar organized by Jordanian NGOs of disabled persons and families of disabled women and girls;

(iii) Concert by Jordanian girl musicians at the Royal Cultural Centre (RCC);

(iv) Field visit to a rehabilitation centre for disabled girls in Amman.

11. The Seminar was organized in accordance with the timetable contained in the programme of work (annex II).

## B. ATTENDANCE

12. The Seminar was attended by disabled women, families of disabled persons, regional and international experts participating in an individual capacity, representatives of NGOs, mass media experts and inter-agency task force members from other United Nations organizations. A substantial proportion of the participants in substantive discussions were themselves disabled (see annex I for the list of participants).

## C. OPENING OF THE SEMINAR

13. The Seminar was opened by Her Royal Highness Princess Majida Ra'ad Bin Zeid. In her opening statement, Princess Majida Ra'ad Bin Zeid referred to her experience over the years in the field of women and disability in Jordan. The double handicap experienced by Arab disabled women was first due to their impairment and second due to negative social attitudes. Disabled women had been denied the opportunities to realize fully their potential and to integrate into Arab societies, regardless of the significant progress towards improving the status of women in general. Disabled women in the region did not benefit from the dividends generated by the development process. Disabled girls in the ESCWA region were less likely to attend school than able-bodied children. Disabled women's participation in the labour force was very limited in the region. The negative social attitudes towards impaired women (social handicap) constituted a much more serious problem than the impairment itself. Arab

disabled women were unaware of their own abilities and talents because of their socialization process, as one of the causes of their social isolation. Several major causes of disability in the region were consanguinity, genetic incompatibility between parents, insufficient perinatal care, birth accidents leading to the onset of cerebral palsy (CP), insufficient immunization and accidents at home, in traffic and at work. Armed conflicts in the region were a cause of both men's and women's disabilities. The role of the family was important in terms of prevention, awareness raising, rehabilitation, education and training and assistance in finding gainful employment. However, formal and professional services were needed to supplement family care. Princess Majida concluded her statement by praising the successful preparation and organization of the Seminar.

14. During the opening session, the Deputy Executive Secretary of ESCWA addressed the Seminar and welcomed the participants. She said that the Seminar was important not only because of the issue of disabled women but because the response to the issue could demonstrate how the positive elements of the Arab culture and traditional values, and the responsibilities of modern Arab States, could respond to such a challenging issue. Disability affected women and girls more seriously, not only when they were disabled themselves but also as primary caretakers of disabled family members, namely as mothers or wives of disabled individuals. Disabled women and girls in the ESCWA region were still excluded from mainstream development and marginalized in Arab society regardless of the significant progress made during the last few decades, in many countries of the region, towards improving the overall status of women in general. Several negative trends had emerged, including the impact of the economic recession and the severe debt burden at the national and family levels, wars and civil strife and regional tensions, environmental degradation and human mismanagement, the sharp imbalance between population growth and resources and the continued shortage of qualified manpower to assist disabled persons as well as the lack of financial resources. The Arab family was the major informal institution primarily responsible for the socialization, training and education of children, and Arab women played a very important role as caretakers of disabled family members, particularly in CBR settings. Several specific areas should be targeted for future action at the regional level, namely: measures for prevention and early intervention in childhood disability including genetic counselling, provision of adequate training services and counselling for caretakers, provision of appropriate technical, moral and financial support to family caretakers and adaptation of appropriate technical aids/technologies for disabled persons.

## D. Election of officers

15. The following persons were elected at the plenary session and working group discussions:

Plenary session

| | |
|---|---|
| Chairperson | Madiha El-Safty |
| Vice Chairpersons | Heba Hagrass<br>Rabab Charafeddine |
| Rapporteur | Amal Nahas |

Working group sessions

| | |
|---|---|
| Group 1: | The situation of women and their social integration |
| Moderator | Heba Hagrass |
| Rapporteur | Amal Ibrahim |
| Group 2: | Childhood disability and the role of the family (particularly mothers) |
| Moderator | Madiha El-Safty |
| Rapporteur | Nazek Nosseir |
| Group 3: | The role of grass-roots NGOs in community-based rehabilitation |
| Moderator | Representative of ESCWA |
| Rapporteur | Nimra Tannous El Said |

## E. ADOPTION OF THE AGENDA

16. The Seminar adopted the following agenda:

Plenary session

1. The extent and nature of the problems of disabled women and children in the ESCWA region, with particular emphasis on their socio-economic characteristics and the level of their social integration (or social marginalization).

2. Childhood disability and the role of the family (particularly mothers) in terms of prevention, early intervention and rehabilitation.

3. The role of grass-roots NGOs (particularly women's NGOs) in community-based rehabilitation (CBR).

4. Terms of reference of the United Nations Inter-Agency Task Force on Disability in the ESCWA Region.

Working group session

On the basis of the plenary discussions, three small working groups on main subjects (1) - (3) will develop regional guidelines on the role of the family in promoting social integration of disabled women in the ESCWA region.

## F. DOCUMENTATION

17. Seven background documents on the agenda items were prepared specifically for the Seminar, made available in English, Arabic or both. Four additional papers were presented to the Seminar. Furthermore, 12 United Nations documents on the subject of women and disability were distributed to participants. Various disability-related database documents (ESCWA documents) were also available for reference and distribution at the information desk throughout the Seminar. A complete set of documents was sent to each participant who confirmed her/his participation prior to the Seminar for review and study. (The list of documents is contained in annex III.) A few core documents were made available in the format of speech-synthesizer, tape-recorded voice for blind persons.

## G. PROCEEDINGS

18. The programme of the Seminar covered several core themes on the role of the family in integrating disabled women in the region. In accordance with the timetable contained in the programme of work, the first day was dedicated to presentations and discussions in the plenary session, and the second day was devoted to the United Nations Inter-Agency Task Force Meeting and working-group discussions on three core issues on women and disability. During the first day, in the first agenda item of the plenary session, a Social Affairs Officer of ESCWA briefly reviewed the situation of disabled women and their social integration in the ESCWA region, based on statistical analysis of their socio-economic characteristics. She also demonstrated computer-based synthesized speech technology for both totally and partially blind persons. An Egyptian disabled participant, Ms. Heba Hagrass, briefly reviewed the situation of disabled women and the extent of their problems in Egypt. A Jordanian participant, Ms. Amal Nahas, outlined various programmes provided for disabled women in Jordan

and summarized the overall situation of disabled women in Jordan. A disabled participant (Ms. Maha Barghouthi) from the Jordan Sports Federation for the Handicapped presented a paper on the situation of disabled women in Jordan, based on her personal experience. Ms. Amal Ibrahim (a blind participant from Lebanon) briefly presented her paper. In the discussion that followed these presentations, participants raised questions and made comments.

19. In the second agenda of the plenary session, two speakers, Ms. El-Safty and Ms. Nosseir, briefly reviewed childhood disability and the role of the family in terms of prevention, early intervention and rehabilitation. It was followed by a presentation by Ms. Charafeddine, a participant who was the mother of two severely mentally retarded children in Lebanon and actively involved in activities of grass-roots NGOs (parents organizations) there. Two representatives of UNICEF briefly summarized the UNICEF perspective on disability and the focus of its programme in the field of childhood disability, disability prevention and the role of the family.

20. Mr. Abdullah Al-Khatib presented a paper on the role of grass-roots NGOs in both institutional and community-based rehabilitation services in Jordan.

21. During the morning of the second day, the United Nations Inter-Agency Task Force Meeting on Disability was held. The Task Force further elaborated its terms of reference and identified future activities to be coordinated by various United Nations agencies. The report of the Task Force Meeting is submitted in annex IV.

22. During the afternoon of the second day, three parallel working group sessions were held on the extent and the nature of the problems of disabled women and children and the level of their social integration (social marginalization), childhood disability and the role of the family and the role of grass-roots NGOs. During the course of the substantive discussions, several realistic recommendations covering each subject were made. These were considered by the drafting committee and incorporated in the regional guidelines (see chapter II of the present report).

23. The cultural programme of the Seminar covered a variety of activities to enhance the creativity and capabilities of Arab disabled women and men. Throughout the Seminar, the exhibit halls of the Royal Cultural Centre featured continuous exhibits of artistic work by disabled persons and a charity bazaar organized by Jordanian NGOs. A concert of Arab music played by Jordanian blind girl musicians was held at 8 p.m. on 17 October 1994, organized by the Regional Centre for Training and Rehabilitation of Blind Girls.

### H. PRESENTATION OF THE RECOMMENDATIONS OF THE PLENARY SESSION

24. The recommendations prepared by the drafting committee were presented to participants during the closing of the Event on 18 October 1994.

## I. CLOSING SESSION

25. During the closing ceremony on 18 October 1994, which was attended by Her Royal Highness Princess Majida Ra'ad Bin Zeid, a brief closing statement was made by the Chief of the Social Development Issues and Policies Division. The draft report was also distributed to participants. Princess Majida officially closed the Seminar and congratulated participants on its successful completion.

## II. RECOMMENDATIONS FOR ACTION AND REGIONAL GUIDELINES

26. During the deliberations at the plenary session, the participants reached agreement on the following framework within which regional activities could be developed in the future. The regional guidelines for future action were endorsed as a basis for the regional strategy of ESCWA to further the implementation of the World Programme of Action concerning Disabled Persons.

27. The following recommendations were formulated by Group 1.

Group 1: The situation of disabled women and the level of their social integration

*Preamble*

The issue of disabled women should be addressed within the overall framework of women's development in the Arab world.

Cultural aspects of the ESCWA region should be taken into consideration in the process of planning and implementation of activities for disabled women.

(1) Major causes of disability and problems of disabled women:

(a) Negative social attitudes towards disabled women, social isolation and the stigma of being a disabled woman;

(b) Low self-esteem/self-image of disabled women;

(c) Lack of public awareness (e.g., negative image of disabled women in the mass media);

(d) Difficulty in marriage (partially due to the practice of arranged marriage), and failure to recognize the sexuality of disabled women;

(e) Difficulty faced by disabled mothers regarding child care;

(f) Practice of kinship marriage and the lack of genetic counselling;

(g) Accidents (at home, in the workplace, etc., owing to exhaustion and the depletion of women's energy);

(h) Armed conflicts (particularly modern high-tech wars) and their aftermath (e.g., Iraq, Lebanon and Palestine);

(i) Longer life expectancy of women in general (old-age disability);

(j) Lower level of education of disabled women (e.g., illiteracy of disabled women);

(k) Income insecurity experienced particularly by Arab disabled women in view of their special needs;

(l) Marginal level of employment of disabled women and the lack of vocational training for them;

(m) Lack of trained manpower for rehabilitation of disabled women;

(n) Vocational training programmes for disabled women, which do not meet the current needs of the labour market (e.g., too traditional);

(o) Lack of information, literature and statistics (e.g., under-enumeration of Arab disabled women);

(p) Lack of legal provisions to support disabled women at home (providing home care);

(q) The lack of integration of disabled women into development programmes/projects for women in general;

(r) The need for developing special programmes/projects for disabled women;

(s) The special need to organize disadvantaged groups of the disabled such as groups of mentally retarded women and multiply disabled women.

(2) Action-oriented recommendations

The Seminar expressed the need to review the above priority problems for future concrete action, tied to targets within specific time-frames, with particular emphasis on the following specific areas of action:

(a) Major socio-economic-political trends in the region such as armed conflicts, poverty or the current insufficient development of Arab women in general should be recognized as the ultimate causes of disability in the region;

(b) Public awareness campaigns should be initiated in order to change negative public attitudes towards disabled women;

(c) Disabled women should be integrated into overall development projects for women in general; however, special projects for the disabled should be developed as well;

(d) Rehabilitation institutions and centres for disabled persons should work together with the family in order to ensure the fullest integration of disabled women (persons);

(e) Arab women's significant role in the formal setting of rehabilitation should be recognized. Education and training of qualified Arab female resources for disabled persons should be stressed;

(f) Community-based rehabilitation, within the framework of primary health care and income generation, should be promoted with the active participation of the families and the disabled women themselves;

(g) High fertility without proper birth spacing (including too early and too late pregnancies) should be avoided;

(h) Kinship marriage practices in the region are a negative socio-cultural factor in hereditary disabilities. In this regard, education of women should be emphasized as it is more effective than education of men. A public awareness programme on the dangers of intermarriage among close relatives should be introduced, and proper genetic counselling should be provided by the member States;

(i) Education and employment are singled out as major problems facing Arab disabled women. Mainstreaming of Arab disabled women in education, training and employment should be promoted;

(j) Marriage is one of the major problems of Arab disabled women. Marriage counselling services should be made available to them, and public awareness should be promoted to change negative attitudes towards the marriage of disabled women;

(k) Priority should be given to disabled working mothers in child-care facilities;

(l) Arab disabled women are under-enumerated owing to prevailing social attitudes. In addition, there is a lack of literature on this subject. Studies on disabled Arab women should be promoted. Families should be encouraged to cooperate in data collection for national censuses and other surveys. The statistical data should be gender-specific. Definition, classification and standardization of disabilities should be initiated at the regional level.

(m) Transfer of new technologies should be promoted as powerful instruments for the fullest integration of disabled women in daily life.

(n) Committees of disabled women should be formed at the national and regional levels. Sub-committees of different categories of disabled women (deaf women, blind women, etc.) should be formed as well.

28.The following recommendations were formulated by Group 2.

Group 2: The role of the family

(1) Major causes and problems related to female and childhood disability and the role of the family:

(a) Poverty and malnutrition of mother and child (e.g. low-birth-weight babies, vitamin A/D deficiency, iodine deficiency, iron deficiency);

(b) Inadequate immunization of mothers/children;

(c) Lack of awareness and/or failure of early detection/intervention;

(d) Improper birth spacing, too early or too late pregnancies;

(e) Lack of appropriate prenatal, perinatal and postnatal supervision, and delivery without attendance of proper medical staff;

(f) Lack of sanitary conditions in the homes and lack of proper medical services in some communities of the ESCWA region;

(g) Practice of kinship marriage and the lack of genetic counselling;

(h) Family illiteracy;

(i) Shortage of proper technical, moral and financial support for family care from responsible authorities;

(j) Imbalance of shared responsibility from all family members.

(2) Action-oriented recommendations related to the role of the family in coping with female and childhood disability

(a) The role of the family should be emphasized in terms of prevention of childhood disability. Literacy and overall development of Arab family members, especially women/mothers, should be considered prerequisites for the prevention of, and early intervention in, disability in the region;

(b) The family should keep abreast of new developments related to the treatment of disability and make use of new methods and appropriate technologies;

(c) Proper birth spacing and avoidance of too early and too late pregnancies should be observed;

(d) Breast-feeding and proper weaning practices, as well as a balanced diet for both mothers and children, should be encouraged;

(e) Health authorities should be responsible for primary health care of the mother and child (e.g. immunization and prenatal, perinatal and postnatal care), including prevention and early detection of disability, as well as early intervention. Primary health care should also cover the treatment of disabling conditions and monitoring of the validity of vaccines. The family's role is significant for its effective implementation;

(f) Bad habits during pregnancy such as intake of alcohol, drugs and smoking should be avoided, in addition to avoiding exposure to X-rays;

(g) The family's role in terms of overcoming the disabled child's psychological barriers should be recognized;

(h) The family should involve a disabled child in family/community activities;

(i) Appropriate technical, moral and financial support including family counselling should be provided to families taking care of the disabled, starting from the beginning of the disability;

(j) Rehabilitation institutions and centres for disabled persons should work together with the family in order to ensure the fullest integration of disabled women (persons);

(k) Family support programmes with short-term relief for families with disabled children should be instituted;

(l) Government economic support should be given to families of disabled persons, in order to provide relief measures in the home (e.g., facilitate the employment of a helper or maid);

(m) Free, compulsory education should be available for all children including disabled children;

(n) The family/community should promote integration of disabled persons into recreation programmes.

29.The following recommendations were formulated by Group 3.

Recommendations of Group 3

NGOs would play either a direct or indirect role in the following areas:

(a) To emphasize the role of public awareness and the mass media in the social integration of disabled women;

(b) To aid and guide less experienced families, taking advantage of the experience of families with disabled persons. This should be done through small groups of parents with similar interests, sometimes in the presence of a counsellor. These meetings could take place at the home of one of the families;

(c) To strengthen the moral support and affection provided by family members of disabled persons;

(d) To coordinate the disability-related functions between the concerned ministries and the NGOs, under the umbrella of one authority in order to avoid problems of overlapping and competition among ministries;

(e) To allocate 5 per cent of big companies or institutions profits as taxes to be invested in NGO projects;

(f) NGOs should supply data and statistics, particularly in preparation for the forthcoming national census in Jordan;

(g) To strengthen coordination among NGOs;

(h) To establish a joint United Nations-NGO office which would function as an advisory and training service for individuals interested in setting up grass-roots NGOs in their respective areas of interest. The office should provide:

- ☼ Advisory services for the procedures and regulations on setting up an NGO;
- ☼ A library of documentation on NGOs and related topics, and materials to spread awareness of international affiliation with other NGOs;
- ☼ Training of interested individuals in management, budgeting, fund-raising and project evaluation procedures;

(i) To use special education classes within regular schools, rather than establish new special schools for the disabled;

(j) To change and improve negative traditions and concepts in order to improve the general conditions of disabled persons;

(k) To strengthen self-confidence and independence of the disabled;

(l) To follow up on the implementation of laws and regulations protecting the rights of the disabled;

(m) To promote the participation of disabled persons in decision-making;

(n) To encourage the creativity of disabled persons and promote accomplishments;

(o) Adaptation of the infrastructure and buildings to meet the needs of the disabled and follow up on its implementation;

(p) To involve the participation of the disabled in the process of the formulation of legislation;

(q) To strengthen the sponsorship of disabled persons by their financially well-off relatives;

(r) To charge the minimum amount of service fees for public services and allocate them to aid disabled persons;

(s) To expand existing projects rather than to duplicate projects, in order to control expenses;

(t) To create appropriate job opportunities for disabled persons.

## III. SUMMARY OF PRESENTATIONS AND DISCUSSIONS

### A. PLENARY SESSION

30. Under agenda item 1, a Social Affairs Officer from the ESCWA secretariat presented a background paper, entitled "The Situation of Disabled Women and their Social Integration in the ESCWA Region" (E/ESCWA/SD/1994/WG.1/2). The presentation included a careful analysis of statistical data on socio-economic characteristics of disabled women in the ESCWA region, with statistical data from Bahrain, Egypt, Jordan, Qatar and the Syrian Arab Republic regarding major causes of impairment/disability such as poverty, lack of immunization, high fertility rates and late pregnancies, women's (mothers') illiteracy, old age disabilities, negative social attitudes and social isolation, kinship marriage and armed conflicts. The presentation also included statistical data concerning problems facing disabled women such as illiteracy and lack of education, lack of employment and difficulty in marriage. In addition, the presentation covered case-studies (in Jordan, Palestine and Saudi Arabia) about the congenital disability caused by too late pregnancy, the lack of immunization against rubella and marriage-related difficulties owing to hereditary impairments. The presentation included several recommendations for concrete measures including: overall women's development; marriage/genetic counselling; genetic testing; public awareness campaigns; studies, statistics and research; training of mothers in terms of prevention; early intervention; rehabilitation and social integration of disabled women; and mainstreaming of disabled women in terms of education, employment and social life. The presentation concluded with a demonstration of the application of a computer-based speech synthesizer for blind individuals in order to emphasize the importance of new technologies.

31. The above presentation was followed by the presentation of Ms. Hagrass—an Egyptian expert, who was physically disabled and in a wheelchair. Based on her personal experience and her careful research, she identified several major problems facing disabled women in Egypt. For the women, those problems included social isolation, being the object of pity and charity, illiteracy, insufficient education and training, difficulty in marriage, suppression of their sexuality, financial insecurity (particularly old, disabled women) and negative stereotypes of the women. In her paper, Ms. Hagrass recommended several core issues for future action, including preventive measures against congenital impairments; immunization; measures for early detection and intervention; public awareness; education and training of disabled women; development of low-cost vocational rehabilitation facilities for disabled

women; promotion of disabled women's organizations and organizations of parents; compilation of statistics of disabled women; and active mass media involvement.

32. Ms. Amal Nahas from Jordan briefed the participants about various programmes and services provided to disabled women in Jordan. Her presentation covered the content of Jordanian legislation (Law 12 of 1993) for the welfare of disabled persons with regard to rights to education including higher education (according to the disabled person's capabilities), to social integration, to medical care and to prevention and employment (according to her/his capabilities) and the 2 per cent employment quota for enterprises employing over 50 people. She listed education, special education, training, employment, implementation of legislation, family guidance and awareness as priority issues for disabled women in Jordan.

33. A physically disabled woman representing the Jordan Sports Federation for the Handicapped outlined, based on her private experience, the various needs of disabled women in Jordan, including respect, self-esteem, affection, acceptance and a sense of security. She emphasized the role of the family in terms of the disabled person's social integration, self-reliance and normalization.

34. Ms. Amal Ibrahim (a blind participant from Lebanon) briefly covered the problems facing disabled women, particularly blind women in Lebanon. She referred to the lack of disability statistics in Lebanon. She said that blind women in Lebanon faced a more serious problem than blind men in mobility as they feared being taken advantage of by others.

35. With regard to agenda item 2, Ms. El-Safty reviewed childhood disability and the role of the family in terms of prevention, early intervention and rehabilitation. In presenting her paper (E/ESCWA/SD/1994/WG.1/7), she emphasized the role of the family in promoting social integration of disabled girls/women. She said that there was under-numeration in the statistics on disability in the region and that they were unreliable, partially owing to the lack of unified classification and terminology of "disability" in the region. She emphasized the need for reinforcement of several concrete measures to be taken by the family of a disabled woman. Those measures included acceptance of the disability, breaking down the sense of "social stigma" because of having a disabled girl, refraining from neglecting a disabled girl, avoiding too much pressure on disabled girls and keeping expectations realistic (particularly for mentally retarded girls), positive attitudes of the family towards female disability through mass media awareness programmes, acceptance of the concept of "normalization", breaking down the sense of guilt, particularly among siblings of a disabled girl, prevention and early intervention in the family and provision of emotional support and affection to a female disabled family member.

36. Under the same agenda item, Ms. Nazek Nosseir presented her paper (E/ESCWA/SD/1994/WG.1/6). In her presentation, she stressed the importance of the

role of mothers in family care. She emphasized the importance of overall empowerment of women for the effective implementation of preventive measures of childhood disability. She said that preventive measures were the most effective and had the largest cost-benefit ratio, taking into consideration the financial and emotional costs and burdens on the disabled child and the family. She identified several prenatal, perinatal and postnatal causes of childhood disability in the ESCWA region, including poverty, endogamous marriage, low-birth-weight babies, malnourishment or lack of proper nutrition for mothers and children, childbirth with the attendance of traditional midwives rather than qualified medical staff, lack of sanitary conditions, accidents, and armed conflicts. She listed several measures which mothers could observe for prevention, early detection and intervention in disability and rehabilitation of the disabled child. Those measures included avoiding endogamous marriage, balanced nutrition for the mother and the baby, safe childbirth, general education and literacy of the mother, spacing between pregnancies, immunization of mothers and children against preventable diseases, psychological and moral support and making efforts to integrate the disabled child into family and community activities. She recommended activities within the framework of primary health care (PHC) and maternal and child health (MCH) programmes, with active involvement of the mother.

37. Finally, Ms. Charafeddine (from Lebanon), the mother of two severely mentally retarded children, briefed the participants on her own experience in family care. She emphasized that, on the occasion of the International Year of the Family, an appeal should be addressed to the international community to recognize the rights of the disabled and their families. She listed several causes of disability in the region affecting women, including kinship marriage, lack of balanced nutrition, intake of alcohol, drugs and cigarettes, exposure to X-rays and lack of vaccination against contagious diseases. The insufficiency of qualified medical staff to ensure safe childbirth for women was another cause of disability. The role of the mother was essential, particularly in determining the degree of the disability of the child, in drawing up a programme to develop the capabilities of the child, in determining her/his goals, in keeping abreast of new developments related to the treatment of disability, in making use of new methods and equipment and in making use at home of all the locally available educational and rehabilitation equipment and games. However, the institutions, centres and associations engaged in rehabilitation could not be ignored as their task was to ensure the full participation of the disabled in society in cooperation with the family. Cultural, social, religious, industrial and labour organizations should be urged to stop discriminating against women, especially mothers, and should support woman's role as a full partner in the building of society.

38. A representative of the United Nations Children's Fund (UNICEF) regional office for the Middle East and North Africa briefly explained the UNICEF perspective on disability, and the focus of its activities in the field of women and disability and the role of the family. UNICEF activities were based on the Convention on the Rights of the Child, which proclaims universal rights for all children, including the right to

services, education and full social integration. The UNICEF focus was on "rights" rather than on "charity". She said that disabled persons should be consulted by the mass media in terms of appropriate presentation of disabled individuals. Finally she emphasized the importance of CBR; UNICEF focused on CBR in promoting breast-feeding and oral dehydration programmes to combat diarrhoea.

39. His Royal Highness Prince Firas Bin Ra'ad, representing the UNICEF field office, made a brief presentation on UNICEF activities. He said that UNICEF provided technical support to local projects implemented by local organizations in the field of prevention, early intervention and rehabilitation. He listed five ongoing projects technically supported by UNICEF, including one in Al-Mafraq executed by the Jordanian/Swedish Medical Association, the mobile clinic project implemented by the Al-Husseini Society for the Physically Handicapped and another project for CP executed by the Queen Alia Fund. UNICEF promoted income-generating projects for disabled persons and their families.

40. Under agenda item 3, Mr. Abdullah Al-Khatib presented his paper (E/ESCWA/SD/1994/WG.1/4) on the role of grass-roots NGOs, particularly NGOs of disabled women, in community-based rehabilitation in Jordan. He presented statistical data on the number of voluntary societies for disabled persons and the type of services they offered. Only 2 per cent of disabled women were provided with services from various groups working for disabled persons in Jordan. Rehabilitation activities were undertaken by various NGOs for disabled women in Jordan. A CBR approach was important and the family should be actively involved. Examples of grass-roots NGOs active in integrating disabled women, using the CBR approach, they included organizations such as the Jordanian Association for Family Planning and Protection, which dealt with aspects of family planning including birth spacing, prevention of congenital cases, health education for pregnant women and mothers, and public awareness, and the Jerash Women's Society, a leader in employing disabled women. Voluntary societies and grass-roots NGOs should be provided with financial support. It was important to initiate small-scale (self-help) projects for disabled women, particularly in rural communities, in order to promote disabled women's integration and empower them. The concept of "independent living" should be introduced.

## B. Working group discussions

(Working Group 1)

41. Based on the plenary discussion, Working Group 1 reviewed the issue of the causes of disability in the region, the problems faced by Arab disabled women and recommendations and guidelines for future action. The participants mentioned several problems of disabled women including difficulty in marriage, sexuality, lack of education, illiteracy and marginal level of employment. It was agreed that disabled

women should be integrated into overall development projects for women in general as much as possible; however, there might be a need to establish separate projects for them if such integration was not possible. It was agreed that disabled women's issues should be tackled within the overall development of Arab women in general, taking into consideration the cultural aspects.

(Working Group 2)

42. Working Group 2 discussed the role of the family (under agenda item 2). The participants began by identifying the problems of disabled women. It was felt that the term "high fertility" was sensitive, and it was agreed that the term should be replaced by references to proper birth spacing to avoid too early and too late pregnancies. The issue of "illiteracy" was raised: although education was important, sometimes "ignorance" could still be manifested even if the mother was literate if she was too much confined to the family circle. The issues of the lack of regular medical check-ups for children, the need for primary health care, the lack of proper medical care, and the misuse of medicines without a doctor's prescription were raised. It was important to involve the entire family and avoid giving the sole responsibility and entire burden of family care to the mother. It was the responsibility of the family, with the proper support from the specialists, to help disabled persons to make the most of their abilities. The lack of child-care facilities for disabled children was also discussed. A number of recommendations were formulated by the Group.

(Working Group 3)

43. Bearing in mind the characteristics of the Arab NGOs and the Arab family, Working Group 3 focused on the change in trends from a "charity and welfare" approach to participation and involvement of the disabled persons themselves. The new approach was emphasized. Examples of successful experiences of CBR programmes were mentioned. The role of the mother was emphasized as a major source of social rehabilitation of disabled children. Cooperation between families of disabled persons and the concerned NGOs was important in view of the strong family ties and well-established family structure prevailing in the Arab region, whereby the Arab family still functioned as the major source of socio-economic and psychological support for its members.

44. At the local community level, Working Group 3 defined the role of NGOs as follows:

(a) Providing services and/or equipment, e.g. mobile clinics;

(b) Carrying out fund-raising activities, such as lotteries and marches;

(c) Providing vocational training and sheltered workshops;

(d) Providing guidance for disabled persons regarding their own small-scale income-generating projects;

(e) Acting as partners and pressure groups at the decision-making level;

(f) Promoting awareness regarding the rights of the disabled, and acting as a support for disabled persons;

(g) Initiating their own creative projects as well as assisting in funding;

(h) Promoting informal education, not only for disabled persons, but for people around them and the community as a whole;

(i) Ensuring the sustainability of a given programme, or project, through proper planning.

45. The United Nations Inter-Agency Task Force Meeting on Disability was held on the second day. The Meeting elaborated its terms of reference and discussed various activities to be coordinated by United Nations agencies in the field of disability.

*Annex I*

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*Annex II*

## PROGRAMME OF WORK

Sunday, 16 October 1994

| | |
|---|---|
| 8-10 a.m. | Registration |
| 9 a.m. | Opening by Mr. Abdullah Al-Khatib, President of the Executive Council of the General Union of Voluntary Societies, of bazaar by NGOs and exhibit of artistic work by disabled women. |
| 10-11 a.m. | Opening of the Seminar at the Royal Cultural Centre in Amman under the patronage of Their Royal Highnesses Prince Ra'ad Bin Zeid and Princess Majida Ra'ad Bin Zeid. |
| | 1. Speech by the Deputy Executive Secretary of ESCWA. |
| | 2. Speech by Her Royal Highness Princess Majida Ra'ad Bin Zeid. |
| 11-12 a.m. | Reception |
| 12-2 p.m. | Lunch break |
| 2-6 p.m. | Plenary session |
| 2-2.15 p.m. | Adoption of the agenda and organization of work |
| | Session on: |
| 2.15-3.15 p.m. | (Agenda item 1) |
| | The extent and nature of the problems of disabled women and children in the ESCWA region, with particular emphasis on their socio-economic characteristics and the level of their social integration (or social marginalization). |
| | A. Presentation of paper by the ESCWA secretariat. |

B. Presentation of paper by Ms. Heba Hagrass, physically disabled participant from Cairo.

C. Presentation of paper by Ms. Amal Nahas, Director of the Department of Special Education, Ministry of Social Development.

D. Presentation of papers by Ms. Maha Barghouthi and Ms. Heba Al-Deen, physically disabled participants from the Jordan Sports Federation for the Handicapped.

E. Presentation of paper by Ms. Amal Ibrahim, blind participant from Beirut.

3.15-3.30 p.m. Coffee break

3.30-6 p.m. (Agenda item 2)

Childhood disability and the role of the family (particularly mothers) in terms of prevention, early intervention and rehabilitation.

A. Presentation of paper by Dr. Madiha El Safty, American University in Cairo.

B. Presentation of paper by Dr. Nazek Nosseir, American University in Cairo.

C. Presentation of paper by Ms. Rabab Charafeddine, mother of two mentally retarded children, Beirut.

D. Statement by Ms. Mary Roodkowsky, Regional Programme Officer, UNICEF.

E. Statement by His Royal Highness Prince Firas Bin Ra'ad, Consultant, UNICEF.

Sunday, 16 October 1994 (continued)

| | |
|---|---|
| 3.30-6 p.m. | (Agenda item 3)<br><br>The role of grass-roots NGOs (particularly women's NGOs) in community-based rehabilitation (CBR).<br><br>Presentation of paper by Mr. Abdullah Al-Khatib, President of the General Union of Voluntary Societies, Amman. |

Monday, 17 October 1994

| | |
|---|---|
| 10-12 a.m. | Terms of reference of the United Nations Task Force Meeting and coordination of activities in the ESCWA region (closed Meeting) |
| 12-2 p.m. | Lunch break |
| 2-5 p.m. | Three parallel working sessions to develop the guidelines for promoting social integration of disabled women in the ESCWA region:<br><br>Group 1: The situation of disabled women and the level of their social integration.<br><br>Group 2: The role of the family.<br><br>Group 3: The role of grass-roots NGOs in CBR. |
| 8-9.30 p.m. | Concert performance at the Royal Cultural Centre by blind musicians from the Regional Centre for Rehabilitation and Training of Blind Girls. |

Tuesday, 18 October 1994

| | |
|---|---|
| 9-12 a.m. | Finalizing of the drafting of the regional guidelines by the ESCWA secretariat and the drafting committee.<br><br>Study visit for participants to the Regional Centre for Rehabilitation and Training of Blind Girls, Amman. |
| 12-2 p.m. | Lunch break |

Tuesday, 18 October 1994 (continued)

| | |
|---|---|
| 2-3 p.m. | Adoption of the regional guidelines |
| 3-3.30 p.m. | Closing of the Seminar at the Royal Cultural Centre by Her Royal Highness Princess Majida Ra'ad Bin Zeid. |

Side-Event 16 - 18 October 1994

| | |
|---|---|
| 10 a.m.-5 p.m. | Continuous exhibit of artistic work by disabled women and charity bazaar by NGOs. |

*Annex III*

## LIST OF BACKGROUND DOCUMENTS

### 1. Background documents for the Seminar*

| Document title | Symbol |
|---|---|
| General information for participants (Arabic and English) | E/ESCWA/SD/1994/WG.1/INF.1 |
| Provisional agenda and organization of work (Arabic and English) | E/ESCWA/SD/1994/WG.1/L.1 |
| Annotated provisional agenda (Arabic and English) | E/ESCWA/SD/1994/WG.1/L.1/Add.1 |
| The situation of disabled women and their social integration in the ESCWA region | E/ESCWA/SD/1994/WG.1/2 |
| Women with disability in Egypt (by Heba Hagrass) | E/ESCWA/SD/1994/WG.1/3 |
| The role of grass-roots NGOs, particularly NGOs of disabled women, in community-based rehabilitation (by Abdullah Al-Khatib) | E/ESCWA/SD/1994/WG.1/4 |
| The role of the family and popular action associations in disability prevention, early detection and rehabilitation, in Lebanon (by Rabab Charafeddine) (Arabic, summary in English) | E/ESCWA/SD/1994/WG.1/5 |
| Childhood disability: causes and role of family in prevention, early detection and rehabilitation (by Nazek Nosseir) | E/ESCWA/SD/1994/WG.1/6 |
| Women and disability: the role of the family (by Madiha El-Safty) (Summary in Arabic) | E/ESCWA/SD/1994/WG.1/7 |

* All documents are available in English only unless indicated otherwise.

## 2. Other papers prepared by participants

Family role in the rehabilitation and taking care of the disabled, by Maha Barghouthi, Jordan Sports Federation for the Handicapped

Volume of disability and the situation of the disabled in the world, by Heba Al-Deen, Jordan Sports Federation for the Handicapped

The situation of disabled women in Jordan, by Amal Nahas, Director of Special Education, Ministry of Social Development (Arabic only)

The extent and nature of the problem of disabled women and children in Lebanon, with particular emphasis on their socio-economic characteristics and their social integration (or marginalization), by Amal Ibrahim

## 3. United Nations documents

| Document title | Symbol |
|---|---|
| General Assembly resolution 48/96 on standard rules on the equalization of opportunities for persons with disabilities (Arabic and English) | |
| World Programme of Action concerning Disabled Persons (Arabic and English) | E/ESCWA/SD/1992/WG.1/7 |
| Assessment of the implementation of the World Programme of Action concerning Disabled Persons in the ESCWA region at the end of the United Nations Decade of Disabled Persons and agenda for future action | E/ESCWA/SD/1992/13 |
| Draft long-term strategy to further the implementation of the World Programme of Action concerning Disabled Persons towards the year 2000 and beyond: towards a society for all from awareness to action | E/ESCWA/SD/1992/WG.1/18 |
| Guidelines for the development of organizations of disabled persons | E/ESCWA/SD/1992/WG.1/9 |

* All documents are available in English only unless indicated otherwise.

| Document title | Symbol |
|---|---|
| Families and disabilities 1994 | Occasional Paper Series, No. 10 |
| Final report of the Cultural Event: Disabled Persons in the ESCWA Region: an Event to Mark the End of the United Nations Decade of Disabled Persons (1983-1992) in the ESCWA Region, Amman, 17-18 October 1992 (Arabic and English) | E/ESCWA/SD/1992/WG.1/19 |
| Social statistics and indicators in the ESCWA region | E/ESCWA/SD/89/8 |
| List of organizations for disabled persons (Arabic only) | E/ESCWA/SD/1989/WG.1/34 |
| List of experts in the field of disability | E/ESCWA/SD/1989/WG.1/35 |
| Documentation in the field of disability | E/ESCWA/SD/1993/INF.2 |

*Annex IV*

## REPORT OF THE UNITED NATIONS INTER-AGENCY TASK FORCE MEETING

### Agenda item 1: Briefing on the ongoing ESCWA Seminar

A representative of ESCWA briefed the participants on the plenary discussions of the ongoing ESCWA Seminar on the Role of the Family in Integrating Disabled Women into Society. A list of women-related causes and problems of disabled women was distributed to each participant.

The following comments were made:

- Iron deficiency should be listed as a cause of childhood disability;
- Accidents should be listed as a cause of disability;
- The lack of vocational training for disabled women should be listed as a problem in connection with the low rate of disabled women's participation in the labour force;
- The need for family literacy, as separate from women's/mothers' illiteracy (which is a more significant factor than men's illiteracy) should be stipulated;
- Furthermore, a UNICEF participant suggested that the income-generating aspect of CBR should be included in the last part of the draft recommendations. The desire for male offspring in the Arab world was mentioned as a partial cause of excessively high fertility.

### Agenda item 2: Progress of three planned projects of inter-agency coordination

Concerning the production of local technical aids, another ESCWA representative reported that so far no progress had been achieved. However, she promised to contact the agencies involved and formulate a plan of action at the forthcoming meeting.

Regarding the survey and statistics project in the Palestinian camps, the representative of UNRWA apologized for not submitting comments because he had recently replaced his predecessor and was not yet fully informed on the subject. A representative of UNICEF briefed participants on the progress made so far and the content of previous discussions.

IEC project

A representative of UNICEF explained two components of information, education and communication (IEC): the mass media involvement component and the CBR (grass-roots) component. The mass media component is the so-called traditional IEC element and the CBR component is a new dimension. He emphasized the leading role of UNICEF for IEC and the possible contribution of UNRWA to the CBR (grass-roots) component. In the field of grass-roots IEC, the following four components are listed as priorities: (1) accidents; (2) prenatal services; (3) consanguinity; and (4) genetic counselling. In the mass media dimension, accidents and prenatal services are two major areas of coverage. UNICEF had designed spots for IEC which should be commented on by those concerned.

Another UNICEF participant presented an example of a good TV programme in Jordan, which was geared towards youth, with disabled youth integrated in the programme's approach. She emphasized the importance of including disabled women in regular entertainment programmes.

**Agenda item 3: Inter-agency coordination on the issue of women and disability and the role of the family**

The following issues were identified as issues for inter-agency collaboration:

(a) The practice of kinship marriage and the lack of genetic counselling (ESCWA-UNICEF);

(b) The negative social attitudes towards disabled women and social isolation/stigma (UNRWA, ESCWA and UNICEF);

(c) The lower level of education of disabled women (e.g. illiteracy of disabled women) (UNESCO);

(d) Lack of information, literature and statistics (UNESCO, ESCWA, UNICEF, UNRWA, UNDP);

(e) Lack of public awareness (negative image of disabled women in the mass media) (UNICEF, UNRWA, UNESCO, ESCWA);

(f) Lack of trained manpower for rehabilitation (UNESCO, UNDP, UNRWA);

(g) Insufficient number of grass-roots disabled women's organizations in the ESCWA region and lack of coordination of these organizations at the regional level (UNRWA, ESCWA, UNICEF);

The following agencies are the collaborating agencies for the following cluster projects:

1. CBR Cluster: UNRWA, UNDP, ILO, WHO and ESCWA with UNRWA as the leading agency;

2. Survey/Statistics Cluster: ESCWA and UNRWA with ESCWA as the leading agency;

3. IEC Cluster: UNICEF with UNRWA;

4. CBR and grass-roots Cluster: UNRWA.

A representative of ESCWA suggested that an invitation be extended to the ILO and the WHO regional/field office; the suggestion was adopted by the Meeting.

At the end of the Meeting the Chairperson asked the inter-agency organizations to prepare the provisional agenda and the date for the forthcoming inter-agency meeting for each of the four above-mentioned cluster subjects, and inform other participants before 15 December 1994.

*Appendix*

## LIST OF PARTICIPANTS IN THE INTER-AGENCY TASK FORCE MEETING

| Name | Organization | Title |
|---|---|---|
| Ms. Kay Abe Nagata | ESCWA | Social Affairs Officer |
| Mr. Ali L. Al Dajani | ESCWA | Research Assistant |
| H.R.H. Firas Ra'ad | UNICEF | Consultant for Disability Issues |
| Ms. Moniqa Pettersson | ESCWA | Associate Expert |
| Mr. Firas Gharaibeh | UNDP | Senior Programme Assistant |
| Mr. Jamil Maslamani | UNRWA | Placement—Career Guidance Assistant |
| Ms. Nour Dajani | UNESCO | Literacy Programme Officer |
| Ms. Muna Idris | UNICEF | Senior Programme Assistant |
| Ms. Amal Dajani | ESCWA | Senior Research Assistant |
| Ms. Raeda Al-Zuabi | UNICEF/MENARO | Research Assistant |
| Ms. Dena David | UNICEF/ MENARO | Assistant Programme Officer |
| Ms. Mary Roodkowsky | UNICEF/MENARO | Regional Programme Officer |
| Ms. Fatimeh Atieh | UNRWA | Heath Education Supervisor |
| Mr. Fawzi Abu Hashish | UNRWA | Acting Disabled Programme Officer UNRWA Field Office |

# PART TWO

**Selected Substantive Papers**

# THE SITUATION OF DISABLED WOMEN, THEIR MARGINALIZATION AND MEASURES FOR SOCIAL INTEGRATION IN THE ESCWA REGION*

## INTRODUCTION

Although the status of women varies from one society to another, it has consequences everywhere related to the status of disabled women. Women's unequal status has a negative impact not only on women but on the entire human community. Gender relations and the position of Arab women have been affected by urbanization, industrialization, the expansion of wage labour, political conflicts and warfare in the ESCWA region. Although many countries in the ESCWA region have made significant progress towards improving the general status of women during the last few decades, the tendency is still to exclude disabled women and girls from mainstream development and marginalize them in Arab society. The objectives of this paper are the following:

(a) To outline the major causes of impairments, disabilities and handicaps in the region, particularly those related to women, and especially mothers;

(b) To present and analyse the situation of disabled Arab women on the basis of available disability statistics from seven ESCWA members (Bahrain, Egypt, Jordan, Kuwait, Palestine, Qatar and the Syrian Arab Republic);

(c) To highlight the social problems faced by disabled Arab women by means of several case-studies;

(d) To provide a description of existing services in two countries of the ESCWA region (Bahrain and Jordan);

(e) To assess the role of Arab women (as, *inter alia*, mothers and professionals) in providing services to disabled persons both in informal settings (such as family care) and public settings (such as rehabilitation centres and institutions).

The last chapter contains a summary of the findings of this report and a number of recommendations.

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* This document was prepared by the ESCWA secretariat and originally issued as E/ESCWA/SD/1995/1.

# I. THE STATUS OF ARAB WOMEN IN GENERAL AND THE GENDER RELATIONSHIP

State-sponsored education, accompanied by industrialization and urbanization, has played a major role in creating a generation of more assertive and independent Arab women, and increased participation of women in paid employment has led to changes in household decision-making. However, the integration of Arab women in development is still in a formative stage and is rather limited. Annex table 1 indicates that countries of the ESCWA region have made progress in improving the status of women during the last few decades. Life expectancy at birth in 1992 was above 60 in all countries of the region except Yemen and, parallel to the worldwide trend, women's life expectancy tends to be longer than that of men. Life expectancy is shorter than the world average of 64.7[1] in only two countries, Egypt and Yemen (see annex tables 1 and 2). The demographic stage of most countries in the ESCWA region will continue to be transitional. It is still characterized by relatively high levels of fertility combined with relatively low mortality. The birth rate in Arab families remains high as children are considered to be valuable. The reproductive function of Arab women thus remains one of the most important functions. However, high fertility rates coupled with a lack of proper birth spacing may cause different kinds of impairments.

The statistics in annex table 2 indicate that in 1992 illiteracy levels among women in the ESCWA region were still much higher than those for men despite the steady growth of female literacy during the past few decades. Among individual ESCWA member countries, female literacy rates as percentages of male literacy rates (which should be 100 per cent in principle) range from 49 per cent (Yemen) to 87 per cent (Kuwait). The past few decades have witnessed a gradual but steady increase in the participation of Arab women in the labour force.[2] The participation of Arab women in formal employment has significantly changed their status and gender relations. It has improved their status in the family and given them a role in decision-making.

Regarding marriage, the available statistics (see annex table 3) indicate the high percentages of married female youth in the 20-24 age group in the countries of the ESCWA region for 1980. The statistical data indicate that Arab women tend to marry much earlier than their male counterparts; they also tend to marry older men.

The overall impact of the above-mentioned social transformation has been the creation of different segments in the female Arab population. The range of options

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[1] *World Population Prospects: The 1992 Revision* (United Nations publication, Sales No. E.93.XIII.7).

[2] ESCWA, "Review and assessment of the progress achieved for the advancement of Arab women in the light of the Nairobi Forward-looking Strategies" (E/ESCWA/SD/1994/WG.3-WOM/3).

and opportunities available to Arab women has expanded, particularly in limited social segments. These options and opportunities are open to a small portion of the female population, namely, urban females of the middle or upper middle class. New options and opportunities are related to higher education, later marriage, employment, lower fertility, and participation in cultural and social activities and in decision-making. Although a modern middle class has gradually emerged in a number of urban communities in the region, the majority of disadvantaged Arab women (including the poor, the disabled and the rural female population) do not enjoy equal access to these new options. The extent to which disabled women are excluded from mainstream development and are marginalized in society will be reviewed in detail below.

## II. CAUSES OF DISABILITY IN WOMEN

The countries of the ESCWA region have made progress in channelling human and physical resources into one of the objectives of the World Programme of Action concerning Disabled Persons,[3] namely, the "prevention of disability". The "classic" causes of impairment have been declining in relative terms owing to improved child immunization, improved education, better access to health care, improved water and sanitation facilities, lower fertility rates, and better prenatal and perinatal care for women in some countries. However, there are several hereditary, medical, environmental and developmental factors that have caused impairment, and that are particularly relevant to women in the ESCWA region. Before the causes are outlined, the definitions of "impairment", "disability" and "handicap" must be clearly understood. According to the World Health Organization (WHO), "impairment" is defined as "any loss or abnormality of psychological, physiological or anatomical structure or function"; "disability" is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being"; and "handicap" is defined as "a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for the individual".[4] This section examines the causes of "impairment" in purely medical terms and the causes of "disability" and "handicap" in social terms, focusing on those which are particularly relevant to Arab women in the region.

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[3] United Nations, *World Plan of Action concerning Disabled Persons* (New York, United Nations Department of Public Information, August 1992) (DPI/933/Rev.1).

[4] Quoted in International Labour Office *Vocational rehabilitation and the employment of the disabled: a glossary* (Geneva), ISBN 92-2-002571-X.

Precise data on the prevalence of impairment at the regional level are scant. Furthermore, recent attempts at surveying impaired individuals are fragmented and incomplete. However, existing data indicate that the figures are high. According to a 1982 ESCWA report entitled "Disabled persons in the ESCWA region: features and dimensions of the problem and a regional plan of action", the number of disabled individuals was estimated at 8 million at the regional level—an estimate that may be well below the current figure.[5] The 1981 Arab Declaration on Action for Disabled Persons estimated that there were 15 million disabled persons in the Arab world.[6] By applying the balanced sex ratio of 50/50, the estimates of female disability/impairment could range from 4 million (using the 1982 ESCWA estimate) to 7.5 million (the 1981 Arab Declaration estimate) in the ESCWA region. It is presumed that out of these 7.5 million disabled women, at least 50 per cent (3.75 million) live in rural and relatively poor communities. Being totally isolated, relatively immobile and homebound, they may be deprived of assistance, rehabilitation, services and basic human rights. WHO estimates that 7 to 10 per cent of the world's population have some kind of disability, and the rate is higher in rural communities. If women who care for a disabled family member are added to the statistics, approximately 14 to 20 per cent of women are affected by disability in one way or another.

The causes of impairment in the region can be grouped into two major subcategories: socio-economic and environmental factors, including medical aspects such as prevention and immunization; and factors related to certain cultural values and social barriers. During the ESCWA Regional Seminar on the Role of the Family in Integrating Disabled Women into Society (held in Amman from 16 to 18 October 1994, and hereafter referred to as the ESCWA Regional Seminar), several major causes of disability among women in the ESCWA region were identified by the participants. These include: mothers and children suffering from poverty and malnutrition; inadequate sanitary conditions in homes and the lack of proper medical services; inadequate immunization of mothers and children; improper birth spacing and early or late pregnancies; the practice of kinship marriage and the lack of genetic counselling; the lack of appropriate pre-, peri- and postnatal supervision; accidents; armed conflicts; the longer life expectancy of women in general (old-age disability); and negative social attitudes towards disabled women as a result of the stigma attached to disabilities, leading to social isolation and thereby creating a social "handicap".

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[5] ESCWA, "Assessment of the implementation of the World Programme of Action concerning Disabled Persons in the ESCWA region at the end of the United Nations Decade of Disabled Persons and agenda for future action" (E/ESCWA/SD/1992/13).

[6] ESCWA, "Developmental social welfare issues: (a) inter-regional consultation on developmental social welfare policies and programmes" (Note by the Executive Secretary), presented at the fourteenth session of ESCWA, held in Baghdad from 31 March to 5 April 1987 (E/ESCWA/14/7).

## A. POVERTY

The most significant socio-economic and environmental factor is poverty. The correlation between poverty and impairment/disability can be proved by the higher prevalence of disability in Arab rural communities, which suffer from poverty, lack of basic services and negative socio-economic and environmental conditions. For instance, according to the *Population Census of the Syrian Arab Republic, 1981*,[7] the prevalence of disabled persons per 100,000 of the total population was 1,034 in rural areas and 1,008 in urban areas. Rural prevalence rates are higher than urban rates particularly for blindness, deafness and mutism, which are often caused by malnutrition and inadequate hygienic standards. The same national census shows that the rates of blindness per 100,000 females was 147 in rural areas and 101 in urban areas, and the rates of female deafness and mutism were 161 in rural and 147 per 100,000 females in urban areas.

In the Gaza Strip, a significant relationship between mental/multiple disability and poverty was found in the Bureij and Al-Shati communities (see table 1).

TABLE 1. CORRELATION BETWEEN DISABILITY AND THE FINANCIAL STATUS OF FAMILIES WITH DISABLED PERSONS IN THE BUREIJ AND AL-SHATI REFUGEE CAMPS, GAZA STRIP, 1993

*(Percentage distribution)*

| | Financial status | | | | | |
|---|---|---|---|---|---|---|
| | Poor | | Middle level | | Well-to-do | |
| Type of disability | Bureij | Al-Shati | Bureij | Al-Shati | Bureij | Al-Shati |
| Physical | 32 | 44 | 41 | 41 | 27 | 15 |
| Mental/multiple | 42 | 50 | 32 | 33 | 26 | 17 |

*Source:* Gaza National Committee for Rehabilitation and DIAKONIA, *Disability and Rehabilitation Needs in the Gaza Strip: A Survey Report on Bureij and Al-Shati Refugee Camps* (Gaza City, 1993).

*Notes*: Bureij: chi sq. = 8.40324, p = 0.015; Al-Shati: chi sq. = 5.8979, p = 0.05.

[7] Syrian Arab Republic, Office of the Prime Minister, Central Bureau of Statistics, *Population Census of the Syrian Arab Republic, 1981*, quoted from ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

As table 1 indicates, the prevalence of mental and multiple disabilities among the poor (42 per cent in Bureij and 50 per cent in Al-Shati) is significantly higher than that of the well-to-do (26 per cent in Bureij and 17 per cent in Al-Shati). The rate of mental and multiple disabilities tends to decrease from poor to middle level to well-to-do. These disabilities may be a cause of poverty, or poverty may be a determinant of the disabilities. A significant association was also observed between poverty and the number of disabled persons in each family (see table 2).

TABLE 2. CORRELATION BETWEEN FINANCIAL STATUS AND THE NUMBER OF DISABLED PERSONS PER FAMILY IN THE BUREIJ AND AL-SHATI REFUGEE CAMPS, GAZA STRIP, 1993

*(Percentage distribution)*

| Number of disabled within the same family | Financial status of the family in the Gaza Strip, 1993 | | | | | |
|---|---|---|---|---|---|---|
| | Poor | | Middle level | | Well-to-do | |
| | Bureij | Al-Shati | Bureij | Al-Shati | Bureij | Al-Shati |
| One disabled | 31 | 40 | 41 | 42 | 28 | 18 |
| Two disabled | 32 | 43 | 43 | 43 | 25 | 14 |
| Three disabled | 48 | 66 | 25 | 23 | 27 | 11 |

*Source:* Gaza National Committee for Rehabilitation and DIAKONIA, "Disability and rehabilitation needs in the Gaza Strip: a survey report on Bureij and Al-Shati refugee camps" (Gaza City, 1993).

*Notes*: Bureij: chi sq. = 20.03357, p = 0.005; Al-Shati: chi sq. = 43.35005, p = 0.0000.

Of those families with one disabled member, 31 per cent in Bureij and 40 per cent in Al-Shati are poor, and the number of disabled persons in a family increases parallel to the poverty factor. Of those families with two disabled members in the same family, 32 per cent in Bureij and 43 per cent in Al-Shati are poor. Of those families with three disabled members, 48 per cent in Bureij and 66 per cent in Al-Shati are poor. This reveals a clear correlation between poverty and the number of disabled persons within the same family.

Various manifestations of poverty are related to disability in general and childhood disability in particular. Malnutrition and unsanitary conditions (including inadequate access to clean water, sanitary facilities and basic medical services) pose the greatest dangers to "safe" parenting.

## B. MALNUTRITION

Poverty causes malnutrition, which is one of the main factors contributing to disabilities in children and women. Poverty results in the failure of many children to grow to their full mental and physical potential. Over 100 million persons around the world are currently estimated to be disabled as a result of malnutrition.[8] During the ESCWA Regional Seminar, malnutrition in both mothers and children (signified by low-birth-weight babies and deficiencies in vitamins A and D, iodine and iron) was considered a major cause of disability in the region. Malnutrition is more prevalent among girls than among boys in some parts of the ESCWA region. For instance, several studies in Palestine indicated higher malnutrition rates among girls than among boys in many of the Palestinian communities studied owing to the selective neglect of female children.[9]

Vitamin A deficiency (a major cause of blindness) and iodine deficiency (a major cause of goitre and cretinism leading to subnormal mental development, deaf-mutism and paralysis) are recognized as major causes of childhood blindness and mental retardation, respectively.[10] It is estimated that 6 per cent of Jordanian children were suffering from malnutrition in 1991, and that about 20 per cent of them were consuming less than the required amount of nutrients.[11] It has been reported that malnutrition is common among both pregnant Egyptian women and female children.[12] To compensate for the lack of nutrients, the child's metabolism drops, causing low blood pressure. The amount of body fat decreases, and the body draws on its reserves, depleting muscle instead of body fat and delaying bone growth or even causing deformation of bones.

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[8] United Nations Children's Fund (UNICEF), *The State of the World's Children 1994* (New York, Oxford University Press, 1994).

[9] United Nations Conference on Trade and Development (UNCTAD), *Health Conditions and Services in the West Bank and Gaza Strip* (by Rita Giacaman) (UNCTAD/ECDC/SEU/3), 1994.

[10] ESCWA, "UNICEF-assisted programmes and global strategy on childhood disability prevention and rehabilitation" (E/ESCWA/SD/89/WG.1/3), a paper presented by UNICEF at the Conference on the Capabilities and Needs of Disabled Persons in the ESCWA Region (held in Amman from 20 to 28 November 1989). UNICEF has been assisting iodine deficiency control programmes throughout the world through iodization of the local salt supply. It is estimated that 800 million malnourished people are at risk, and cretinism itself affects about 3 million. More than 80 per cent of these individuals are in Asia as a whole.

[11] Fahed Al Fanek, "A battle on the social front", *Jordan Times* (Amman), 10 April 1994.

[12] Heba Hagrass, "Women with disability in Egypt", a paper submitted to the ESCWA Regional Seminar on the Role of the Family in Integrating Disabled Women into Society (held in Amman from 16 to 18 October 1994).

Chronic anaemia (leading to subnormal child development) is caused by iron deficiency. A study conducted by the United Nations Relief and Works Agency for Palestine Refugess in the Near East (UNRWA) in 1992 on morbidity patterns in the refugee camps indicated a high prevalence of anaemia among children who visited the clinics (66 per cent of children older than six months and younger than one year of age, 63 per cent of two-year-old children and 45 per cent of three-year-old children).[13]

The 12 months following birth are crucial to a child's development. During this stage brain development is almost completed, so even if nutrition later improves, the child's physical and mental development will be impaired. Breast-feeding is recommended in the early months of a child's life; however, the quality and quantity of the mother's breast milk are greatly affected by her own nutritional status. A lack of high quality breast milk may impair the child's immune system and expose him or her to illness. The lack of clean water and sanitation in some communities causes diarrhoea and contributes to malnutrition.

Low weight at birth causes various kinds of childhood disabilities and at the same time contributes to malnutrition. It is a major cause of maternal mortality and birth trauma. During the ESCWA Regional Seminar, it was agreed that low birth weight (a manifestation of poverty) was a major cause of childhood disability. The statistics in annex table 2 indicate that, during the period from 1980 to 1992, the proportions of children aged 0 to 4 years who were moderately to severely underweight stood at 30 per cent in Yemen, 23 per cent in Oman, 12 per cent in Iraq, 10 per cent in Egypt and 6 per cent in Kuwait (where per capita GNP is US$ 16,150). In oil-rich Oman, 5 per cent of children were severely underweight.

The ESCWA Regional Seminar identified the delivery of a child without the attendance of proper medical personnel as one of the major causes of disability in women in the region. The infant mortality rates in Iraq and Yemen remain higher than the world average. The traditional midwife is still a popular health practitioner in some countries of the ESCWA region, particularly in rural and Bedouin communities. For instance, in Jordan, there is an acute shortage of nurses with proper training in midwifery. While the number of trained midwives increased from 127 in 1951 to 625 in 1991, the ratio remains low, necessitating the continued dependence on untrained traditional midwives.[14] Assistance in childbirth rendered by such unqualified individuals can result in a number of complications for both mother and child, some

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[13] United Nations Children's Fund (UNICEF), "Health services", *Mother & Child in Jordan*, a newsletter about human development issues (Amman, UNICEF and Al Kutba, Publishers, 1994).

[14] Ibid.

of which can lead to permanent disabilities.[15] Asphyxia at birth (which is more common in home deliveries) is a major cause of mental retardation and cerebral palsy. There is an urgent need to introduce measures to eliminate birth-related accidents that lead to disabilities. This can be achieved by supporting safe delivery and mothering practices.

These childhood disabilities are likely to continue through adolescence and into adulthood. As a result of malnutrition, these disabled children tend to suffer throughout their lives. This is particularly true for disabled girls, as they will be given the lowest priority for rehabilitation and other services. Later, they, too, may give birth to underweight babies, and they may not be able to manage early intervention inasmuch as they will most likely be illiterate and ignorant—a vicious circle.

### C. Lack of sanitation, immunization and early intervention

Poverty is often manifested by human deprivation. The profile of human deprivation can be measured by the level of unsanitary living conditions, the lack of access to safe drinking water and the lack of access to health services. These factors, combined with insufficient immunization, are causes of infectious diseases leading to the onset of various impairments in some communities of the ESCWA region. In some cases, the aftermath of armed conflicts has aggravated the situation. The ESCWA Regional Seminar singled out inadequate sanitary conditions in homes and inadequate medical services in some communities of the ESCWA region as major causes of disability.

Indeed, the lack of adequate water and safe sanitation frequently causes illness, poor growth and impairment. These factors contribute to the spread of contagious diseases, leading to permanent impairment in some cases. Inadequate hygienic practices are closely related to diarrhoea, which is still the major cause of stunted child growth. According to the UNICEF report, *The State of the World's Children 1994*,[16] during the period 1988 to 1991, 70 per cent of the rural population in Yemen had no access to safe water, and 39 per cent had no access to adequate sanitation. In the Syrian Arab Republic, 42 per cent of the rural population had no access to safe water, and 32 per cent had no access to medical services. In Egypt, half the total population and 74 per cent of the rural population had no access to adequate sanitation. Even in

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[15] Madiha Al-Safty, American University in Cairo, "Women and disability: the role of the family" (E/ESCWA/SD/1994/WG.1/7); and Nazek Nosseir, "Childhood disability: causes and role of family in prevention, early detection and rehabilitation" (E/ESCWA/SD/1994/WG.1/6). Both papers were submitted to the ESCWA Regional Seminar on the Role of the Family in Integrating Disabled Women into Society, held in Amman from 16 to 18 October 1994.

[16] See note 8.

Oman, with its per capita GNP of US$ 6,120 (in 1991), only 40 per cent of its rural population had access to adequate sanitation services. Only 30 per cent of Saudi Arabia's rural population has access to adequate sanitation (per capita GNP in Saudi Arabia was US$ 7,820 in 1991). In some places, the lack of clean water causes water-borne diseases such as river blindness, leading to permanent disabilities.

During the Regional Seminar, inadequate immunization of both mothers and children was singled out as a major cause of disability in the region. Indeed, in recent decades there has been substantial progress regarding immunization for pregnant women and children in most countries of the ESCWA region. However, universal immunization has not yet been fully achieved in the region.

The importance of immunizing women who are or may become pregnant cannot be overstated. The statistics in annex table 2 indicate that the rates of pregnant mothers immunized against tetanus from 1990 to 1992 ranged from 13 per cent (Yemen) to 97 per cent (Oman). For the eight reporting countries, the rate was between 60 and 70 per cent in three countries (Egypt, Qatar and Saudi Arabia), between 30 and 50 per cent in two countries (Iraq and Jordan) and less than 30 per cent in two countries (Kuwait and Yemen).

The vaccination of women against rubella (German measles)[17] prior to child-bearing is among the most important preventive measures against multiple childhood disabilities (blindness and mental retardation). One Palestinian woman living in Saudi Arabia has two totally blind children, the blindness being due to her infection with rubella during her pregnancies. The second time, doctors misdiagnosed her rubella virus as cured despite her persistent inquiries about the risk of having another blind child (see chapter III, section D, case-study 2).

The immunization of newborn children is also important. Meningitis during infancy was found to be a major cause of childhood cerebral palsy (CP) in the sample survey conducted in Jordan.[18] Also, poliomyelitis contracted in childhood often causes permanent paralysis. The immunization of children against poliomyelitis (a disease that can cause permanent physical disability) is not universal in some countries. At the global level, the rate of immunization (by means of a vaccine during the

[17] Maternal rubella frequently causes severe and multiple impairments (blindness combined with mental retardation) in a newborn child. Prenatal vaccination against rubella and a perinatal examination is an effective preventive measure. Women should be cautioned never to be immunized against rubella during pregnancy, however, as a "live vaccine" is used which is very likely to cause fetal impairment/deformity.

[18] Staffan Janson and others, "Severe mental retardation in Jordanian children", *Bulletin of the Consulting Medical Laboratories*, vol. 6, No. 2 (Amman), April 1988.

12 months after birth) has already reached 80 per cent.[19] The percentage of fully immunized children (one year old) against poliomyelitis during the period from 1990 to 1992 was only 62 per cent in Yemen and 64 per cent in Iraq. According to international statistics, in Iraq, the level of poliomyelitis immunization fell significantly from 1990 to 1992 (from 75 per cent to 64 per cent) owing to the aftermath of the Gulf crisis (see annex table 2). According to the latest statistics released by the country, the number of poliomyelitis cases increased by a factor of 7.5 during the period from 1989 to 1993.[20] Even in Jordan, where medical services are relatively extensive, a UNICEF report[21] noted that about 10 per cent of Jordanian children were not yet vaccinated against poliomyelitis, diphtheria, pertussis or tetanus, and 20 per cent were not vaccinated against measles.

### D. High fertility rates and the lack of birth spacing

As noted in the previous section, fertility is high in the ESCWA region. High fertility combined with the lack of spacing between births may cause health problems for both the mother and child. During the ESCWA Regional Seminar, the participants agreed that improper birth spacing, often indicating early or late pregnancies, was a major cause of disability in the Arab world, and proper birth spacing was recommended.

Women's level of education is often the key determinant of the fertility level in a given country. Some scholars attribute the absence of a rapid decline in fertility in the Arab world to the fact that traditional values still favour large families. High fertility[22] indicates a lack of spacing, early child-bearing or rearing (teenagers), and late child-bearing or rearing (after age 37). All of these, especially late child-bearing, create a high risk of bearing an impaired child. Pregnancy after the age of 37 entails the high risk of having a child with Down's syndrome (a congenital disorder caused by a chromosomal defect, characterized by mental retardation and physical defects). According to a Jordanian survey in 1993, almost 14 per cent of the mothers surveyed

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[19] See note 8.

[20] Iraqi national report submitted to the International Meeting on the Development of a National Plan for Community-Based Rehabilitation, held by the World Health Organization in Beirut from 28 November to 1 December 1994.

[21] United Nations Children's Fund (UNICEF), "Infant and child health", *Mother & Child Health in Jordan*, a newsletter about human development issues (Amman, UNICEF and Al Kutba, Publishers, 1994).

[22] Total fertility rates per woman range from 3.6 (Lebanon) to 7.7 (Yemen) in the region, which is much higher than the world average (3.31 per woman).

were above age 35 when they conceived their last child. The older the mother, the greater the chance of a high-risk pregnancy.[23]

According to data on disability in Qatar,[24] the number of children with an impairment as a proportion of all children ever born[25] increases with the mother's age. The number of disabled children increases from 2.8 per 1,000 children even born for mothers under 25 years of age, to 6.2 per 1,000 for mothers aged 25 to 29, and to 9.6 per 1,000 for mothers aged 40 to 44.[26] The figures for surviving children with a disability show a similar picture. The *Qatar Child Health Survey 1991* concluded that the risk of certain congenital impairments increased with the mother's age (see table 3).

Late pregnancy frequently causes Down's syndrome in newborns. For instance, according to the survey conducted in Jordan, the mean age of the mothers of newborns with Down's syndrome in the experimental group was 37.[27] The amniocentesis test—especially for relatively older pregnant women (over 36 to 37)—has proven to be an effective diagnostic measure for Down's syndrome. In fact, abortion is permitted in some countries of the region (for example, Bahrain, Iraq, Kuwait and Qatar) in cases of severe fetal impairment.[28] Aysha (a Palestinian woman now living in Jordan) was merely 20 years old when she became the second wife of Mohammed (then 49 years old) in 1948. Both Aysha's first husband and Mohammed's first wife had been killed by Israeli soldiers in the first Arab-Israeli war. Aysha had 12 (surviving) children with Mohammed, and when she delivered their last child, Abdul Aziz, she was 48 years old. Aysha did not take the amniocentesis test, nor was she aware of the possibility of bearing a mentally retarded baby. Abdul Aziz was born with Down's syndrome. (Further details of this story are provided in case-study 1 in section D of chapter III.)

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[23] Jordan, Ministry of Health, Department of Statistics, and the United Nations Children's Fund, *Assessment of the Nutritional Status of Preschool Children in Jordan* (Amman, 1993).

[24] Qatar, Ministry of Health, *Qatar Child Health Survey 1991*, Abdul-Jalil and others, eds. (Doha, Ministry of Health, 1991).

[25] Including those who died.

[26] However, partially, the increase in the mother's chronological age in proportion to the number of disabled children reflects the corresponding increase in the average age of children and their longer and cumulative exposure to risks.

[27] See note 18.

[28] *Abortion Policies, a Global Review* (United Nations publication, Sales No. E.94.XIII.2).

In the early stage of the child's life, breast-feeding constitutes the most important source of nutrition. There is a risk that bottle-feeding may contribute to malnutrition in the child and abnormal development. It is often the case that Arab women who have numerous, closely spaced pregnancies stop breast-feeding and depend instead on powdered milk or alternative nutritional sources. The percentages of mothers breast-feeding at 6 months after birth decrease significantly: 32 per cent in Kuwait, 40 per cent in Lebanon, 45 per cent in Iraq, and 52 per cent in Saudi Arabia (annex table 2). This may lead to health problems for the newborn. The statistics in annex table 2 indicate that the proportion of mothers breast-feeding for the first 3 months after birth range from 47 per cent (Kuwait) and 50 per cent (Lebanon) to 91 per cent (Saudi Arabia) for the period 1980 to 1991. However, the rate drops significantly even in Saudi Arabia at 6 months.

TABLE 3. NUMBER OF CHILDREN EVER BORN WITH IMPAIRMENT ACCORDING TO THE MOTHER'S AGE, QATAR, 1991

| | Children with impairment (ever born) | | Live children | |
|---|---|---|---|---|
| Age of mother | (per woman) | (per 1,000 children) | (per woman) | (per 1,000 children) |
| Under 25 | 0.006 | 2.8 | 0.004 | 1.9 |
| 25-29 | 0.020 | 6.2 | 0.020 | 6.3 |
| 30-35 | 0.033 | 7.7 | 0.028 | 6.9 |
| 35-39 | 0.040 | 7.3 | 0.038 | 7.4 |
| 40-44 | 0.058 | 9.6 | 0.049 | 8.6 |
| 45-49 | 0.066 | 9.2 | 0.063 | 9.8 |
| Average of all age groups | 0.033 | 7.6 | 0.030 | 7.2 |

*Source:* Qatar, Ministry of Health, *Qatar Child Health Survey 1991*, Abdul-Jalil Salman and others, eds. (Doha, Ministry of Health, 1991).

According to the 1990 *Jordan Population and Family Health* (JPFH) survey,[29] 90 per cent of mothers breast-fed their babies during the first 3 months of life, with the proportion falling to 68 per cent from the seventh to the ninth month, and to just 60 per cent from the tenth month to one year after delivery. Surprisingly, the lowest breast-feeding rate was found for mothers in upper-income families, followed by those

[29] *Jordan Population and Family Health* survey (1990), as quoted in: United Nations Children's Fund (UNICEF), "Infant and child health", *Mother & Child in Jordan*, a newsletter about human development issues (Amman, UNICEF and Al Kutba, Publishers, 1994).

living in refugee camps. The most depressing finding is that in some countries of the region (for example, Oman), girls are breast-fed for a shorter period than boys. In Oman in 1989, the average duration of breast-feeding for girls was 7.55 months compared with 8.9 months for boys.[30]

Some Arab scholars[31] argue as well that the mother's attention and energy tend to be scattered if she has too many children; with each child receiving less care, the likelihood of accidents occurring increases. Other international scholars also support the view that high fertility rates reduce the amount of time, care and resources available for each child, which might contribute to increased child morbidity and accident rates.[32]

Proper pre-, peri- and postnatal care is also essential for impairment prevention, and early intervention and rehabilitation can very often either partially or totally prevent or correct childhood impairments. Deliveries should be performed by qualified medical professionals (doctors or qualified nurses/midwives) so that any unnecessary trauma or complications may be avoided. During the Regional Seminar, it was agreed that the delivery of children without the attendance of the proper medical staff constituted one of the major causes of childhood disability in the region. Trauma during delivery may result in the occurrence of disability; the prevalence of deliveries by unqualified, traditional midwives is a serious problem in many countries of the ESCWA region, particularly in rural areas. The figures in annex table 2 indicate that the percentages of births attended by trained medical personnel range from 16 per cent (Yemen) to 99 per cent (United Arab Emirates) for the period 1983 to 1992; the rate is still 50 per cent or below in four countries of the region (Egypt, Iraq, Lebanon and Yemen).

### E. Insufficient education and illiteracy among Arab women in general

Although there has been significant general improvement in Arab women's participation in education at all levels and in female illiteracy eradication, the results

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[30] United Nations Children's Fund, Regional Office for the Middle East and North Africa, *Sex Differences in Child Survival and Development, 1990*, Evaluation series, No. 6 (1990).

[31] Nazek Nosseir, "Women and disability in the ESCWA region", *Proceedings of the Conference on the Capabilities and Needs of Disabled Persons in the ESCWA Region* (E/ESCWA/SD/1992/2); and Heba Hagrass, "Women with disability in Egypt", a paper submitted to the ESCWA Regional Seminar on the Role of the Family in Integrating Disabled Women into Society, held in Amman from 16 to 18 October 1994 (E/ESCWA/SD/1994/WG.1/3).

[32] Napaporn Havanon and others, "The impact of family size on wealth accumulation in rural Thailand", *Population Studies*, vol. 46 (1992).

are not yet completely satisfactory. Many studies have confirmed the positive correlation between women's illiteracy and child mortality and morbidity. Illiteracy is also a major barrier to social integration. The education of women could significantly reduce the incidence of childhood disability, as rates are much higher among the children of illiterate women than among those of mothers who have received even just a basic education.[33] Women's illiteracy is both a cause and a result of underdevelopment, as the mother is most often the key to a child's socialization and human development. In a study on Egypt, female illiteracy was proven to be a significantly relevant variable. An illiterate woman lacks an awareness of health issues, including those related to medical care during pregnancy; among other things, she tends to prefer the traditional practitioner when seeking health services. All of this frequently results in unnecessary problems and complications.[34] During the Regional Seminar, the importance of family literacy was stressed; it was agreed that the literacy and overall development of Arab family members, especially women and mothers, should be considered prerequisites for the prevention of and early intervention in disability in the region.

According to the *Qatar Child Health Survey 1991*,[35] illiterate women tend to run a much higher risk of having a child with an impairment or disability. As shown in table 4 below, the number of children with disabilities per 1,000 children ever born to illiterate women is 8.4, compared with only 6.9 for literate women. The difference is significant among women aged 45 plus: 10 compared with 6.3 per 1,000 children ever born. Among women aged 35 to 44, the figures are 9.5 for illiterate mothers and 7.0 for literate mothers. Among women under 35 years of age, however, the incidence of childhood disability is slightly higher for the literate mothers' group. The higher risk of disability among children born to illiterate mothers increases with the age of the mother, as it is presumed that apart from the increased likelihood that disabilities will occur as the result of, for example, illness, home accidents, or the lack of early intervention—all related to the illiteracy of mothers—there is the additional risk of congenital disabilities occurring among the children of older mothers. The higher incidence of disabled children among illiterate women of over 35 age group thus indicates the greater risks of congenital disability—perhaps caused, *inter alia*, by the lack of prenatal care.

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[33] See note 8.

[34] See note 12.

[35] See note 24.

TABLE 4. QATARI CHILDREN WITH DISABILITIES PER 1,000 CHILDREN EVER BORN ACCORDING TO THE MOTHER'S AGE AND BACKGROUND, QATAR, 1991

| Mother's literacy level | Mother's age | | | Total (all ages) |
|---|---|---|---|---|
| | <35 | 35-45 | 45+ | |
| Illiterate | 5.4 | 9.5 | 10.0 | 8.4 |
| Literate | 6.8 | 7.0 | 6.3 | 6.9 |
| Combined average | 6.4 | 8.3 | 9.2 | 7.6 |

*Source*: Qatar, Ministry of Health, *Qatar Child Health Survey 1991*, Abdul-Jalil Salman and others, eds. (Doha, Ministry of Health, 1991).

Some experimental research conducted in Jordan in 1988[36] involving 203 mentally retarded children and their parents showed that mental retardation was much more prevalent among the children of illiterate and less educated mothers (the overall level of education among the retarded children's mothers was lower than the national average). The same pattern is found here as in the Qatari survey. One third of the mentally retarded children's mothers in the Jordanian sample survey were found to be illiterate; only 1 per cent were university graduates (see table 5).

Furthermore, it has been proved that there is a significant negative correlation between the level of the mother's education and consanguineous marriage, which is considered a major cause of congenital disability in the ESCWA region; this will be reviewed in greater detail below. Annex table 2 indicates that female adult literacy rates (literate females as a percentage of literate males, which should be 100 per cent in principle) are relatively lower in the ESCWA region, ranging from 49 per cent in Yemen and 54 per cent in Egypt to 83 per cent in Lebanon and 87 per cent in Kuwait.

When it comes to the education of disabled women themselves, there is no need to mention that the equivalent literacy rates for disabled women are much lower than those for able-bodied women and disabled men (further details are provided below). Annex tables 4 and 5, respectively, indicate the male-female distributions and ratios of the disabled population relative to the total population in the Syrian Arab Republic in 1981, according to both type or category of disability and literacy status/educational attainment. Illiteracy among disabled Syrian women is 1.32 times that of disabled Syrian men. Only one third (34 per cent) as many disabled women as disabled men

[36] See note 18.

hold university degrees. As there is a similar trend within the able-bodied population, this analysis indicates that there is a clear gender-based differentiation regarding literacy for both the able-bodied and disabled Syrian populations (see table 6).

TABLE 5. EDUCATIONAL LEVELS OF THE PARENTS OF MENTALLY RETARDED CHILDREN IN JORDAN, 1984 TO 1987

*(Percentage distribution)*

| | | Education of the mother (national average) in the early 1980s | |
|---|---|---|---|
| Educational level | Father of the retarded child (mean age of 35) | Mother of the retarded child (mean age of 28) | Mother of the average child (mean age of 25.27) |
| Illiterate | 18 | 33 | 30.48 |
| Primary | 23 | 16 | 25.79* |
| Preparatory | 18 | 15 | 26.19 |
| Secondary | 10 | 8 | 11.23 |
| Diploma | 10 | 8 | 2.96 |
| University | 5 | 1 | 1.26 |
| Unknown | 16 | 19 | |

*Sources*: Staffan Janson and others, "Severe mental retardation in Jordanian children", *Bulletin of the Consulting Medical Laboratories*, vol. 6, No. 2 (Amman), April 1988; and S.A. Khoury and D. Massad, "Consanguineous marriage in Jordan", *American Journal of Medical Genetics*, vol. 43 (1992), pp. 769-775.

* Excluding those who "read and write" (0.35 per cent).

These findings can be summed up by the following vicious cycle: (a) a girl is born with an "impairment"; (b) she is not given priority for rehabilitation or services, so she remains illiterate; and (c) she does not have the means to become economically or socially independent; and this leads to (d) permanent "disability" and the increased likelihood that the girl will become a "handicap" to society. All of this constitutes what is often called the "handicap dynamism".

TABLE 6. PERCENTAGE DISTRIBUTION OF THE ILLITERATE POPULATION AND THOSE WITH UNIVERSITY DEGREES, BY SEX AND DISABILITY, SYRIAN ARAB REPUBLIC, 1981

| | Illiteracy among the disabled | Illiteracy among the total population | Disabled population with university degrees (BA or MA) | Total population with university degrees (BA or MA) |
|---|---|---|---|---|
| Women | 80.50 | 54.53 | 0.23 | 0.59 |
| Men | 60.51 | 21.95 | 0.68 | 2.48 |
| Both sexes | 67.95 | 37.88 | 0.51 | 1.56 |

*Source*: Syrian Arab Republic, Office of the Prime Minister, Central Bureau of Statistics, *Population Census in the Syrian Arab Republic, 1981*, quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

## F. ACCIDENTS

In many countries today, quite a large proportion of disabilities are caused by accidents and disease. A particularly significant phenomenon in the ESCWA region is traffic accidents: the rates of such accidents are quite high in some countries of the region. In Jordan, for instance, the majority of patients found in emergency rooms are traffic accident victims.[37] In many cases, traffic-related injuries lead to permanent disabilities. Many countries in the region lack the proper infrastructure to absorb the increasing number of automobiles and also lack an effective public transportation system: both problems render them unable to cope with the expanding population. A good public transportation system not only provides an essential service for disabled individuals (to allow them full access), but also constitutes an effective preventive measure against impairment.

During the Regional Seminar, the participants identified various disability-causing accidents among women which occur at home and in the work-place as a result of exhaustion. There is a growing number of working Arab women, and their dual roles have imposed greater psychological pressures on them, as they must now handle work-related responsibilities in addition to their family responsibilities. The lack of proper child-care facilities may aggravate this condition. Good child-care centres are rare in

[37] Association of Japanese Residents in Jordan, "Guidelines for life in Jordan" (Amman, 1989).

many countries of the ESCWA region, and if they exist, the fees tend to be so high that only privileged women can afford them. In the rural communities of Egypt, for example, some women must work from 12 to 16 hours a day to carry out their domestic, child-care and outside work responsibilities, and often find themselves overloaded and exhausted.[38]

A large number of women in the Gulf countries and some Arab expatriates from the Gulf are dependent upon foreign maids (mainly Asians) to provide child care; their care may not be accompanied by sufficient affection or the proper type of attention, which sometimes leads to accidents in the home and childhood impairment. In poor countries and among working-class families, the children in some cases are simply left at home without care when the mothers go to work outside, and the risks of a home accident occurring increase dramatically.

### G. ARMED CONFLICTS AND POLITICAL UNREST

The prolonged armed conflicts in some countries of the ESCWA region have increased the magnitude of the disability problem. Although classical warfare itself affects mainly men, the aftermath of war affects children and women even more (see the case-studies on Asma and Aysha in section D of chapter III). During the Regional Seminar, armed conflicts (particularly modern, "high-tech" wars) and their aftermath (in, for example, Lebanon, Iraq and Palestine) were mentioned as key factors related to female disability in the region. As was proved during the Gulf war, high-tech conflicts affect men, women and children without any discrimination; the same is true of urban warfare, exemplified by the plight of Beirut during Lebanon's tragic civil war. The human efforts towards rehabilitation and reconstruction in the countries of the ESCWA region will last for years and years to come.

The magnitude of disability has increased significantly in Palestine owing to the ruthless suppression of Palestinians during the *intifadah*. During the period 9 December 1987 to 1 October 1990, in addition to 855 fatalities, there were 58,000 casualties resulting from the use of live rounds, plastic-coated metal bullets, rubber bullets, and tear gas; beatings and other forms of assault were also reported in the West Bank and the Gaza Strip. Some 25 per cent of these casualties were women and girls, and 10 per cent of all injuries resulted in permanent disability; this constitutes a substantial increase over the pre-*intifadah* figures of about 60,000 persons with some kind of disability.[39]

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[38] See note 12.

[39] United Nations Relief and Works Agency for Palestine Refugees in the Near East, report submitted to the Eighth Inter-Agency Meeting on the United Nations Decade of Disabled Persons, held in Vienna from 5 to 7 December 1990.

It has been observed that the aftermath of the Gulf crisis has had the most serious impact on vulnerable groups such as women in general and widows in particular, many of whom have no personal assets to buy food or medicine.

The crisis and ongoing sanctions have placed even greater constraints on the already limited resources available for dealing with disability. According to a report of the Food and Agriculture Oraganization of the United Nations (FAO),[40] the food situation in Iraq after the war was so desperate that people were forced to consume cereals normally used for animal feed. The report added that vulnerable groups such as the disabled had increased by 50 per cent in Iraq. Food shortages and the widespread incidence of gastroenteritis appear to have contributed to a very high level of malnutrition, which has caused a large increase in low birth-weight babies. The incidence of certain diseases has also increased dramatically—particularly meningitis (which can cause cerebral palsy and hearing impairment), preventable diseases such as measles and poliomyelitis, and water-borne diseases such as typhoid. The continuing sanctions have been responsible for higher rates of malnutrition; specifically, numerous impairments have been caused by the lack of sufficient vitamin A and/or iodine.[41] According to the same report, psycho-social trauma has been the most serious effect of the aftermath of the Gulf crisis and war for Iraqi children. Immediately after the war, the mortality rate for Iraqi children under five years of age skyrocketed to 380 per cent of its pre-crisis level. It was also estimated that the infant mortality rate rose to 350 per cent of its pre-crisis level. Over 900,000 children—some 29 per cent of all Iraqi children—were reported to be malnourished immediately after the war.

The situation has not improved. By 1994, the aftermath of the war was still affecting the welfare of Iraqi mothers and children, leading to an overall increase in childhood disability. According to the latest statistics released, the number of those malnourished increased by a factor of 17 between 1990 and 1994 (from 102,487 to 1,312,678), and the incidence of poliomyelitis (a possible cause of permanent paralysis) increased by a factor of 7.5 during the period 1989 to 1993.[42]

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[40] Quoted from John M. Goshko, "U.S. expects pact this week on permanent truce in Gulf", *International Herald Tribune* (27 March 1991).

[41] Infant and child mortality and nutrition were assessed by means of a survey of 9,034 households in every region of Iraq: the analysis, entitled *Health and Welfare in Iraq after the Gulf Crisis: An In-Depth Assessment* (October 1991), was conducted in 1991 by the International Study Team, and funded by the United Nations Children's Fund and other private foundations.

[42] See note 20.

## H. WOMEN AND OLD-AGE DISABILITIES

Annex table 2 indicates that, parallel to the worldwide trend, life expectancy for women tends to be longer than that for men in all countries of the ESCWA region; this appears to be a natural phenomenon. Disability greatly increases with ageing, as has been shown in numerous studies. Disability—characterized by a reduction in one's ability to carry out the functions and activities required for daily living and life's roles, and often connected with the outcomes of disease, injury or trauma—may occur at any time during the life cycle, but is more common later in life.

Parallel once again to the worldwide trend, as Arab women tend to outlive their male counterparts, old-age disability is more serious among women. During the Regional Seminar, the participants stressed the relation between longer life expectancy among women in general and female old-age disability. In the ESCWA region as a whole, the incidence of disability among the elderly—particularly among elderly females—is much higher than the average for all groups combined.

Table 7 illustrates this point as it applies in Qatar. According to the 1986 Qatari national census,[43] of the total number of disabled females, 16.04 per cent are over 80 (compared with 12.03 per cent of Qatari men), and 41.83 per cent are over 65 (compared with 33.24 per cent of Qatari men).

A similar trend is found in Bahrain (see table 8). According to Bahrain's *Census of Population and Housing, 1981*,[44] the incidence of disability per 100,000 of the total female Bahraini population was only 1,020 for the combined average of all age groups, but 5,028 for the age group 60 to 64, 5,963 for the age group 65 to 69, and 13,032 for those 70 and above. In other words, about a quarter (24.32 per cent) of females with disabilities were over 70; as the corresponding figure for men was 15.51 per cent, it can be concluded that the old-age disability trend was (and still is) more significant for women in Bahrain. The higher rate of disability among women

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[43] Qatar, national census, 1986, quoted from *Demographic Yearbook 1993*, special issue, "Population ageing and the situation of elderly persons", special article, "Disability statistics of ageing", prepared by the United Nations Statistical Division, Department for Economic and Social Information and Policy Analysis (New York, 1993).

[44] Bahrain, Cabinet Affairs, Directorate of Statistics, *Census of Population and Housing, 1981*, quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

compared with men in the 65-plus age group is reported for the Bureij camp in Palestine as well.[45]

TABLE 7. NUMBER AND DISTRIBUTION OF DISABLED PERSONS IN QATAR BY AGE GROUP, 1986

| Age group | Male disabled | | Female disabled | | Male and female disabled combined | |
|---|---|---|---|---|---|---|
| | Total number | Age group (percentage distribution) | Total number | Age group (percentage distribution) | Total number | Age group (percentage distribution) |
| 65-69 | 28 | 8.86 | 32 | 10.06 | 60 | 9.46 |
| 70-74 | 18 | 5.70 | 22 | 6.92 | 40 | 6.31 |
| 75-79 | 21 | 6.65 | 28 | 8.81 | 49 | 7.73 |
| 80 plus | 38 | 12.03 | 51 | 16.04 | 89 | 14.04 |
| Over 65 (subtotal) | 105 | 33.24 | 133 | 41.83 | 238 | 37.54 |
| All age groups | 316 | 100 | 318 | 100 | 634 | 100 |

*Source*: Qatar, national census, 1986, quoted from *Demographic Year Book 1993*, special issue, "Population ageing and the situation of elderly persons", special article, "Disability statistics of ageing", prepared by the United Nations Statistical Division, Department for Economic and Social Information and Policy Analysis (New York, 1993).

TABLE 8. AGE DISTRIBUTION OF THE DISABLED IN BAHRAIN RELATIVE TO THAT OF THE TOTAL POPULATION BY SEX, 1981

| Age group | Number of disabled Bahraini women per 100,000 females | Percentage distribution of female Bahrainis | | Percentage distribution of male Bahrainis | |
|---|---|---|---|---|---|
| | | Disabled females | Total females | Disabled males | Total males |
| 60-64 | 5 028 | 8.77 | 1.78 | 10.24 | 2.11 |
| 65-69 | 5 963 | 5.79 | 0.99 | 6.61 | 1.17 |
| 70 plus | 13 032 | 24.32 | 1.90 | 15.51 | 1.85 |
| Over 60 (subtotal) | | 38.88 | 4.67 | 32.36 | 5.13 |
| All | 1 020 | 100 | 100 | 100 | 100 |

*Source*: Bahrain, Cabinet Affairs, Directorate of Statistics, *Census of Population and Housing, 1981*, quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base* (1975-1986) (New York, 1988).

[45] Gaza National Committee for Rehabilitation and DIAKONIA, "Disability and rehabilitation needs in the Gaza Strip: a survey report on Bureij and Al-Shati refugee camps" (Gaza City, 1993).

In terms of types of disability, blindness and hearing impairment are the most closely associated with ageing (see table 9). According to the *Population Census in the Syrian Arab Republic, 1981*,[46] the prevalence of blind females per 100,000 of the total female population was only 126 across all age groups, compared with 577 for the age group 60 to 64 and 1,368 for those 65 and over.

The rate of deafness among elderly female populations is very high relative to other age groups in the ESCWA region. In Egypt in 1976, the number of deaf women per 100,000 of the female population was only 7 for all age groups, compared with 17 for the age group 60 to 64, 23 for the age group 65 to 69, 38 for the age group 70 to 74 and 58 for those 75 and above. As the medical and social costs incurred by elderly people with disabilities constitute a burden to the State, and as elderly females tend to be more financially dependent than elderly males, appropriate preventive measures should be stressed.

TABLE 9. BLINDNESS AMONG SYRIAN WOMEN (1981) AND DEAFNESS AMONG EGYPTIAN WOMEN (1976), BY AGE GROUP

| Blind Syrian women by age group (1981) | | Deaf Egyptian women by age group (1976) | | | |
|---|---|---|---|---|---|
| | | | | Age distribution for Egyptian females (percentage) | |
| Age group | Number of blind Syrian women per 100,000 females | Age group | Number of deaf Egyptian women per 100,000 females | Deaf females | Total females |
| All | 126 | All | 7 | 100 | 100 |
| 55-59 | 226 | 60-64 | 17 | 6.12 | 2.65 |
| | | 65-69 | 23 | 4.05 | 1.39 |
| 60-64 | 577 | 70-74 | 38 | 4.07 | 1.19 |
| 65 plus | 1,368 | 75 plus | 58 | 4.93 | 0.98 |

*Source*: Bahrain, Cabinet Affairs, Directorate of Statistics, *Census of Population and Housing, 1981*; and Egypt, Central Agency for Public Mobilization and Statistics, *Population and Housing Census, 1976*, vol. I (Total Republic), Reference No. 93-15111 (Cairo, 1980); both sources quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

[46] See note 7.

The above has touched upon a number of socio-economic and environmental causes of "impairment" in the ESCWA region. While many of those listed affect both men and women, most affect women to a greater extent. The following includes a brief description of some factors related to cultural and social barriers which constitute another type of "disability" or "handicap" and which are especially relevant to women.

## I. SOCIAL BARRIERS AND SOCIAL ISOLATION

Most of the societies in the ESCWA region are traditionally male-oriented, and services are more accessible to men. Negative social attitudes towards impaired women constitute just as much of a "disability" or a "handicap" as the impairment itself. Negative social reactions and rejection may create social barriers which further handicap women who are already disabled. Disabled Arab women tend to believe that they are less important or worthy than their male siblings or able-bodied female siblings; later, the lack of formal education, training and employment opportunities aggravates this deep-seated inferiority complex. One of the biggest problems of disabled Arab women and a major cause of this social handicap is their lack of awareness of their own capabilities and talents—a result of their socialization and upbringing. The role and awareness of the mothers of disabled girl are extremely important in this context. During the Regional Seminar, the participants focused on two important social barriers: (a) negative social attitudes towards disabled Arab women, which lead to social isolation and stigma; and (b) low self-esteem and poor self-image.

Negative attitudes and the social isolation they produce are important causes of social "handicaps" among impaired Arab women; their isolation is clearly reflected in the statistics. A 1993 survey[47] found that in the Gaza Strip, the participation of disabled Palestinian women in public life was much lower than that of disabled men (see table 10).

The table above shows that 31 per cent of disabled women do not move about in their communities at all, compared with only 13 per cent of disabled men. Additionally, a much larger proportion of disabled men than disabled women move about by themselves in the community—64 per cent compared with 44 per cent, respectively (chi sq. = 36.14959, p = 0.000).

The table also indicates that 28 per cent of disabled men do not attend school, 31 per cent attend only lower-level classes, and the rest (41 per cent) attend school normally. However, 48 per cent (almost half) of disabled women do not go to school at all, 19 per cent attend only lower-level classes, and 33 per cent attend school normally (chi. sq. = 10.50871, p = 0.005). The same gender-based differences are

[47] See note 45.

found regarding participation in other social activities. Some 41 per cent of disabled women do not participate in social activities at all, compared with only 29 per cent of disabled men (chi sq. = 21.53889, p = 0.000). Additionally, a significantly higher number of disabled women than disabled men were found to have psychological problems.

TABLE 10. SOCIAL PARTICIPATION AMONG DISABLED MEN AND WOMEN IN THE GAZA STRIP (BUREIJ), 1993

| | Percentage of gender category | |
|---|---|---|
| Type of social activity | Males | Females |
| Move about in community alone | 64 | 44 |
| Do not move about in community at all | 13 | 31 |
| Chi sq. = 36.14959, p = 0.000 | | |
| Attend school normally | 41 | 33 |
| Attend school only at a lower level | 31 | 19 |
| Do not attend school at all | 28 | 48 |
| Chi sq. = 10.50871, p = 0.005 | | |
| Participate in social activities | 49 | 31 |
| Do not participate in social activities | 29 | 41 |
| Chi sq. = 21.53889, p = 0.000 | | |

*Source*: Gaza National Committee for Rehabilitation and DIAKONIA, "Disability and rehabilitation needs in the Gaza Strip: a survey report on Bureij and Al-Shati refugee camps" (Gaza City, 1993).

Social integration appears to be a problem affecting both disabled men and disabled women in the Bureij refugee camp, but disabled women seem to have more serious difficulties than their male counterparts in this respect. In Gazan society, these gender-based differences in levels of social integration can be explained by the prevailing social and parental attitudes towards disabled women. Parents may be less inclined to let their disabled daughters go outside the home; families might be more conscious of the social stigma attached to having a disabled female member. Rather

than run the risk of letting this stigma affect the marriage potential of their other daughters, they may keep their disabled daughter "hidden" from the community.[48]

There is a significant under-enumeration of the disabled female population in most countries of the ESCWA region. For example, Egypt's *Population and Housing Census, 1976*[49] indicated an unusual sex ratio of handicapped males to handicapped females of almost 3 to 1;[50] for mentally retarded persons the ratio was the same in Egypt (3 to 1), and 2 to 1 in the Syrian Arab Republic, according to the *Population Census in the Syrian Arab Republic, 1981*.[51] This is most likely associated with the cultural and social pressures placed upon females to appear marriageable; having a disabled female family member may make other members of the family (particularly female siblings) less marriageable, a circumstance related to the social stigma attached to disability. In such cases, disabled women are either completely ignored or are overprotected by their families.

A similar gender imbalance was found in both Palestine (Al-Yarmouk camp, 1984-1985) and Jordan (1983), indicating significant under-enumeration with respect to female disability (see table 12). In both cases, the female-male sex ratio of disability was about 0.6 (or in other words, 3 disabled women to 5 disabled men). Even if the probability of a slightly higher rate of male disability is taken into account (related to the long-lasting civil conflict in Palestine), this sex ratio is still too skewed.

During the Regional Seminar, the participants agreed that disabled Arab women were under-enumerated as a result of both prevailing social attitudes and the lack of literature on this subject. It was recommended that studies on disabled Arab females be promoted, and that the families of these females be encouraged to cooperate in the collection of data for national censuses and other surveys.

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[48] Much of this section is derived from the analysis of the Gaza National Committee for Rehabilitation and DIAKONIA based on their 1993 disability survey (see note 44).

[49] Egypt, Central Agency for Public Mobilization and Statistics, *Population and Housing Census, 1976*, vol. I (Total Republic), Reference No. 93-15111 (Cairo, 1980), quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

[50] Biologically, the female-male ratio of impairment should be about equal (1 to 1). For instance, in 1993, the numbers of disabled males and females (over 16 years old) in Sweden were 106,000 and 135,000, respectively; the corresponding figures for Austria were 149,000 and 138,500, respectively (United Nations, *Demographic Yearbook*, 1993; see note 42).

[51] See note 7.

TABLE 11. THE GENDER IMBALANCE WITH RESPECT TO THE INCIDENCE OF DISABILITY: THE STATISTICAL UNDER-ENUMERATION OF FEMALE DISABILITY IN EGYPT (1976) AND THE SYRIAN ARAB REPUBLIC (1981)

| | Egyptian census (1976) | | Syrian census (1981) | |
|---|---|---|---|---|
| Sex | Number of disabled per 100,000 people in Egypt | Number of mentally retarded per 100,000 people in Egypt | Number of disabled per 100,000 people in the Syrian Arab Republic | Number of mentally retarded per 100,000 people in the Syrian Arab Republic |
| Females | 158 | 10 | 802 | 114 |
| Males | 443 | 31 | 1 232 | 195 |
| Both sexes | 303 | 21 | 1 022 | 155 |

*Source*: Bahrain, Cabinet Affairs, Directorate of Statistics, *Census of Population and Housing, 1981*; Egypt, Central Agency for Public Mobilization and Statistics, *Population and Housing Census, 1976*, vol. I (Total Republic), Reference No. 93-15111 (Cairo, 1980); and the Syrian Arab Republic, Office of the Prime Minister, Central Bureau of Statistics, *Population Census in the Syrian Arab Republic, 1981*; all sources quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1976)* (New York, 1988).

TABLE 12. THE GENDER IMBALANCE WITH RESPECT TO THE INCIDENCE OF DISABILITY: THE STATISTICAL UNDER-ENUMERATION OF FEMALE DISABILITY IN JORDAN (1983) AND PALESTINE (1984-1985)

| Country | Age group | Number of male disabled per 100,000 males | Number of female disabled per 100,000 females | Female-male ratio |
|---|---|---|---|---|
| Jordan (1983) | 0-14 | 1 340 | 941 | 0.70 |
| | 15-59 | 4 555 | 2 530 | 0.56 |
| | 60 plus | 3 449 | 2 385 | 0.69 |
| | All ages | 539 | 344 | 0.64 |
| Palestine (Al-Yarmouk camp survey, 1984-1985) | 0-14 | 2 406 | 1 645 | 0.68 |
| | 15-59 | 17 878 | 8 493 | 0.48 |
| | 60 plus | 14 625 | 7 841 | 0.54 |
| | All ages | 1 556 | 921 | 0.59 |

*Source*: ESCWA, *Compendium of Social Statistics and Indicators*, third issue (E/ESCWA/STAT/1993/25), 1993.

## J. KINSHIP MARRIAGE

Another cultural and social factor influencing the incidence of impairment is the (often encouraged) practice of marriage between close relatives in the countries of the ESCWA region. In the Arab world the marriage of cousins is commonly practised by all social classes in both rural and urban settings. During the Regional Seminar, the participants all agreed that consanguinity constitutes one of the most significant cultural factors contributing to disability in the ESCWA region.

According to a study conducted by Khoury and Massad (1992), the rate of consanguinity (kinship marriage) in Jordan is about 50 per cent. The observations of several other authors are also included in this study: Khlat and Khudr (1983) indicated that in Beirut, consanguinity (first cousins and more distant relatives) affected a quarter of all marriages; Hafex reported that the level of consanguinity was 28.96 per cent in Egypt; and Al-Awadi and others reported a rate of 54.2 per cent for Kuwait.[52] The genetic disorders caused by consanguinity can result in all types of impairment, including those affecting the mind, the senses and motor skills. Abdallah Al-Khatib, in his national study submitted to the Conference on the Capabilities and Needs of Disabled Persons in the ESCWA Region (held in Amman from 20 to 28 November 1989), stressed the urgent need to draw up legislation to forbid marriage without the necessary medical exams—a first step in preventing hereditary impairments. He also emphasized the need to boost public awareness of the dangers of marriage between close relatives and the consequences of impairment among their offspring.[53] This phenomenon of consanguineous intermarriage is closely related to the status of Arab women in general. The changing role of women has coincided with changes in marriage patterns. With increasing female education and employment, it has become much harder to force a girl into an arranged marriage. In accordance with the improvements in women's education, this traditional form of marriage to kin (particularly the first cousin) is expected to become less common over time. The marriage age of Arab girls has generally risen, and the more contemporary marriages are increasingly based more on mutual understanding and affection between husband and wife than on the family's convenience and perceived interests.

According to a sample survey conducted in Jordan and published in 1992,[54] consanguinity is closely related to the level of women's (wives') education. At the

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[52] The figures and their sources are quoted from a study conducted by S.A. Khoury and D. Massad, "Consanguineous marriage in Jordan", *American Journal of Medical Genetics*, vol. 43 (1992), pp. 769-775.

[53] Abdallah Al-Khatib, "Disability in Jordan", *Proceedings of the Conference on the Capabilities and Needs of Disabled Persons in the ESCWA Region* (E/ESCWA/SD/1992/2).

[54] See note 53.

time of the survey, the overall rate of consanguineous marriage in Jordan was about 50 per cent: 32.03 per cent for first cousins, 6.8 per cent for second cousins and 10.5 per cent for more distant relatives (50 per cent of married couples had no blood relationship). The figures were particularly high for rural communities, where the first-cousin marriage rate was reported to be as high as 37.9 per cent. Education and consanguinity showed a negative correlation: the higher the education, the lower the consanguinity. The survey showed women's education to be much more effective than that of men in this regard. As shown in table 13, female university graduates were shown to enjoy much greater freedom in selecting husbands than other, less-educated groups. Eighty per cent of Jordanian college graduates (wives) had avoided consanguineous marriage (compared with 60 per cent of their male counterparts); they tended to choose their husbands based on friendship, generally avoiding the traditional behavioural patterns in this regard. Interestingly, however, the rate of consanguineous marriage among university-educated Jordanian men is not much different from that of the illiterate group. This might be attributable to a prevailing social factor: there is family pressure on educated Arab men to marry within the family, the general trend being to keep the best males within family boundaries.[55] The overall level of women's education thus appears to be a key factor in reducing the incidence of kinship marriage.

There is also a clear correlation between parental consanguinity and the incidence of severe mental retardation among children. The findings of the study conducted by Staffan Janson and others[56] corroborate those of the above-mentioned study, also reporting an overall consanguineous marriage rate of about 50 per cent in Jordan. The study by Janson and others indicated that the overall kinship marriage rate of 67.5 per cent in the experimental group of parents of severely mentally retarded children was significantly higher than the national average (50 per cent), with the breakdown of the former as follows: 35 per cent for first-cousin marriage; 14.2 per cent for second-cousin marriage; and 18 per cent for marriage between more distant relatives. It was also reported that 21 per cent of the sample children had at least one mentally retarded sibling (11.3 per cent had one retarded sibling, 7.9 per cent had two, 1.5 per cent had three, and 0.5 per cent had four)—a clear indication of genetically based mental retardation.

Interestingly, a very similar figure was found in Egypt, where it was reported that 67 per cent of the parents of disabled persons were close blood relatives, and that

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[55] Ibid.

[56] See note 18.

20 per cent of all disability cases could be attributed to congenital causes.[57] In the Gaza Strip (Bureij camp), significantly higher rates of mental and multiple disability were reported for the children of parents who were blood relations: 43 per cent of the parents of mentally retarded or multiply disabled children were first cousins, and only 30 per cent of the parents were not related at all. The deep-rooted social practice of marriage between cousins appears to be a contributing factor to the incidence of disability throughout the Arab world.

TABLE 13. THE CORRELATION BETWEEN CONSANGUINEOUS MARRIAGE AND THE EDUCATION OF THE SPOUSE

*(Percentage)*

| | Spousal relationship (consanguineous) | | | |
|---|---|---|---|---|
| Level of education | First cousins | Second cousins | Distant relationship | No relations hip |
| Illiterate (wife) | 31.40 | 5.45 | 12.73 | 50.41 |
| Illiterate (husband) | 23.58 | 4.07 | 15.45 | 56.91 |
| Read and write (wife) | 38.15 | 7.13 | 9.25 | 45.47 |
| Read and write (husband) | 32.97 | 7.33 | 8.42 | 51.28 |
| University (wife) | 12.00 | 4.00 | 4.00 | 80.00 |
| University (husband) | 25.11 | 5.94 | 8.22 | 60.73 |

*Source*: S.A. Khoury and D. Massad, "Consanguineous marriage in Jordan", *American Journal of Medical Genetics*, vol. 43 (1992), pp. 769-775.

[57] M.A.S. El-Banna, "The situation of the disabled in Egypt", *Proceedings of the Conference on the Capabilities and Needs of Disabled Persons in the ESCWA Region* (E/ESCWA/SD/1992/2).

# III. PROBLEMS OF DISABLED ARAB WOMEN

According to *Women and Disability*,[58] more disabled women are illiterate and fewer are well educated, they have less access to vocational training, they are less frequently and less gainfully employed, and they are less likely and have fewer opportunities to marry and set up a family. With all these factors combined, their social status tends to be the lowest in any given society. Disabled women in Egypt (and elsewhere), being uneducated, untrained, unemployed and unmarried, are dependent on their parents for support. Losing parents and being left alone with no financial support are a real nightmare for elderly disabled women; training and employment are the only solutions to such a problem.[59] In this chapter, the situation of disabled Arab women with respect to education, employment and marital status is briefly reviewed.

## A. EDUCATION

During the Regional Seminar, the participants singled out the lack of education as a major problem facing disabled Arab women, and recommended the mainstreaming of these women in education and training. Illiteracy rates among disabled women are high compared with those for able-bodied women and disabled men. Table 14 and annex table 4 indicate that in the Syrian Arab Republic in 1981, 80.50 per cent of disabled women were illiterate, compared with 54.53 per cent of the total female population and 60.51 per cent of the disabled male population. Table 14 and annex table 6 show that in Bahrain in 1981, 88.24 per cent of disabled Bahraini women were illiterate, compared with 41.44 per cent of the total Bahraini female population, 73.71 per cent of disabled Bahraini men, and only 21.18 per cent of the total Bahraini male population. Annex tables 4 through 7 indicate the differences in the levels of educational attainment between disabled men and disabled women in the Syrian Arab Republic and in Bahrain (among Bahraini nationals). The illiteracy rate among disabled women is much higher than that for disabled men; in the Syrian Arab Republic, the rate of illiteracy among disabled women was 1.32 times that of disabled men in 1981 (annex table 5). In both Bahrain and the Syrian Arab Republic, the percentage of disabled women who completed higher education was only one third that of the corresponding male population (annex tables 5 and 7).

The connection between female illiteracy and "disability"/"handicap" forms a vicious cycle, as illiterate women are unaware of and/or do not have access to the

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[58] Esther Boylan, *Women and Disability* (London and New Jersey, Zed Books Ltd., 1991), ISBN No. 0-86232-987-6.

[59] See note 12.

means by which they might improve their own economic and social status, and this produces a dependency mentality, which in turn constitutes a social "handicap". Additionally, as illiterate women generally have little idea of the most effective measures for preventing childhood impairment and for early intervention, they are more likely to end up having disabled children themselves.

During their interviews with ESCWA staff (discussed later), Ms. Munira Bin Hindi and Ms. Heba Hagrass (both disabled Arab women) confirmed that family support, particularly support from the mother for education and training, is the most important factor and is a prerequisite for the eventual integration of disabled girls.

## B. EMPLOYMENT

Employment and income security are prerequisites for living with dignity. During the Regional Seminar, the lack of employment opportunities and income security were singled out as major problems for disabled Arab women in particular, in view of their special needs. The mainstreaming of disabled Arab women in training and employment was encouraged.

The participation of disabled women in the labour force is very limited in the ESCWA region. For instance, according to the *Population Census of Kuwait, 1980*[60] only 2.03 per cent of the disabled Kuwaiti female population[61] were economically "active", compared with 9.62 per cent of the total Kuwaiti female population, 19.96 per cent of the disabled Kuwaiti male population, and 66.84 per cent of the total Kuwaiti male population. It should be noted, however, that out of the 97.97 per cent of the economically "inactive" disabled female Kuwaitis, 24.86 per cent were homemakers. Disabled women in this category may be involved in various productive activities at home. On the other hand, not one of the disabled or able-bodied men is considered to be a homemaker. This relatively high proportion of homemakers among disabled women may be at least partially attributable to the standard Arab notion that a woman's major role involves taking care of the home and family. In the Gaza Strip (Bureij camp) as well, disabled women were found to participate in household work and other domestic activities to a much greater degree than disabled men; it was found that some 60 per cent of disabled men did not participate at all in household work, compared with only 32 per cent of women. The participation of disabled women in household work and other domestic productive activities should not be ignored.

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[60] Kuwait, Department of Social Affairs, *Populationi Census of Kuwait, 1980* (Kuwait, Kuwait Government Press, 1982), quoted from "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

[61] The statistics cited here refer only to Kuwaiti nationals.

TABLE 14. PERCENTAGE DISTRIBUTION, BY SEX, OF THE DISABLED AND ABLE-BODIED POPULATIONS WHO ARE ILLITERATE AND WHO HOLD UNIVERSITY DEGREES IN THE SYRIAN ARAB REPUBLIC AND BAHRAIN, 1981

| | Illiterate disabled persons as a proportion of the total disabled population | | Percentage of the total population (both disabled and able-bodied) who are illiterate | | Disabled persons with a university degree as a proportion of the total disabled population | | Percentage of total population (both disabled and able-bodied) with a university degree | |
|---|---|---|---|---|---|---|---|---|
| | Syrian Arab Republic (SAR) | Bahrain (BAH) | (SAR) | (BAH) | (SAR) | (BAH) | (SAR) | (BAH) |
| Females | 80.50 | 88.24 | 54.53 | 41.44 | 0.23 | 0.09 | 0.59 | 1.42 |
| Males | 60.51 | 73.71 | 21.95 | 21.18 | 0.68 | 0.34 | 2.48 | 2.47 |
| Both sexes | 67.95 | 79.28 | 37.88 | 31.36 | 0.51 | 0.23 | 1.56 | 1.92 |

*Source*: Syrian Arab Republic, Office of the Prime Minister, Central Bureau of Statistics, *Population Census in the Syrian Arab Republic, 1981*, quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

TABLE 15. PERCENTAGE DISTRIBUTION OF DISABLED AND ABLE-BODIED KUWAITIS (15 YEARS OLD AND ABOVE) BY SEX AND EMPLOYMENT STATUS, 1980

| | Economically active | Economically inactive | Homemakers |
|---|---|---|---|
| Disabled Kuwaiti women | 2.03 | 97.97 | 24.86 |
| Disabled Kuwaiti men | 19.96 | 80.04 | -- |
| Total Kuwaiti women | 9.62 | 90.38 | 69.86 |
| Total Kuwaiti men | 66.84 | 33.16 | -- |

*Source*: Kuwait, Department of Social Affairs, *Population Census of Kuwait, 1980* (Kuwait, Kuwait Government Press, 1982), quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

With respect to occupational categories (see table 16), 35.29 per cent of the economically active disabled females in 1980 were employed in professional and technical fields, and 41.18 per cent in the clerical field. Disabled Kuwaiti males tended to be employed in services (32.85 per cent), clerical work (24.78 per cent), and production/labour (16.14 per cent)—very similar to the proportions for able-bodied Kuwaiti males.

Table 16. PERCENTAGE DISTRIBUTION OF DISABLED AND ABLE-BODIED KUWAITIS (15 YEARS OLD AND ABOVE) BY SEX AND MAJOR OCCUPATIONAL GROUP, 1980

| Field | Disabled women | Total women | Disabled men | Total men |
|---|---|---|---|---|
| Professional/technical | 35.29 | 51.98 | 14.99 | 9.94 |
| Administrative/managerial | 0.00 | 0.50 | 2.02 | 2.28 |
| Clerical | 41.18 | 35.11 | 24.78 | 22.03 |
| Sales | 0.00 | 0.37 | 4.03 | 5.74 |
| Services | 11.76 | 11.13 | 32.85 | 40.22 |
| Agriculture related | 0.00 | 0.29 | 5.19 | 4.27 |
| Production/labourers | 11.76 | 0.62 | 16.14 | 15.51 |
| Not stated | 0.00 | 0.00 | 0.00 | 0.00 |
| **Total** | 100 | 100 | 100 | 100 |

*Source*: Kuwait, Department of Social Affairs, *Population Census of Kuwait, 1980*, (Kuwait, Kuwait Government Press, 1982). Quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

These gender-based occupational differences may be particularly characteristic of the Gulf countries; the majority of employed disabled Kuwaiti women work in the professional and clerical categories, with a high proportion of them earning good salaries and enjoying social prestige. These relatively "privileged" disabled Gulf women may work for personal satisfaction, intellectual stimulation, social prestige and/or personal development. A disabled Gulf Arab woman with a good academic background is sometimes in a unique position and is able to develop her career on a long-term basis. There seems to be more pressure on disabled men to earn an income, however, regardless of the occupational category.

Annex tables 8 and 9 indicate the differences between disabled men and women in terms of their employment and activity status in Egypt (a non-oil-producing and labour-sending Arab country) in 1976. The tables indicate that, relative to the total disabled Egyptian population, the proportions of students, aged persons, and those unable to work were extremely high for disabled females; the ratio of disabled females

to disabled males in the "aged persons" category was 2.75 to 1, and the corresponding ratio for those "unable to work" was 2.43 to 1.

One interesting finding was that although the proportion of self-employed disabled females was much lower than that of self-employed disabled males (the disabled female rate was only 9.05 per cent of the disabled male rate), it was much higher than the corresponding figure for the total female population (only 2.65 per cent of the total male rate). It appears that some disabled women are engaged in certain types of informal but productive income-generating activities to earn a living and simply to survive. Annex tables 10 and 11 also indicate that in 1976 disabled women were less integrated into the major occupational groups than were disabled men, indicating the failure of these women to occupy themselves productively. In the relatively poor countries of the ESCWA region, self-employment and informal employment may be viable solutions for disabled women. In many rural Arab communities, a number of disabled women are engaged in domestic work and help in agriculture. Some are also heads of households, and many have the same family responsibilities as able-bodied men and women—there are even some who become family heads in old age. In the worst case, unless appropriate policies are promptly formulated for them, poverty can lead to old disabled women being deserted or being taken care of by their families, who may have very little affection for them.

During an interview with ESCWA staff, Ms. Amal Nahas (a specialist in the education and training of disabled persons in Jordan) emphasized that the training of disabled Jordanian women should be geared towards the "immediate incentive" of income generation upon completion of the training, in order to invite support and cooperation from their families, many of whom are reluctant to facilitate such training.

### C. MARRIAGE

Disabled Arab women face more discrimination and difficulty with respect to marriage. During the Regional Seminar, it was noted that difficulties related to marriage (partially attributable to the practice of arranged marriage) constituted a major problem. The only exception to this occurs in the case of mildly retarded women; while men may accept a young and pretty mildly mentally retarded woman, women tend to refuse marriage with a mentally retarded man. Annex tables 12 and 13 indicate that in Jordan in 1983, the percentages of divorced, widowed, and single disabled women were extremely high compared with the corresponding percentages for able-bodied Jordanian women. According to the 1983 statistics, 62 per cent of all disabled women were single, 18 per cent were widowed, only 16.31 per cent were married, and 3 per cent were divorced (see table 17).

The figures for disabled women were also high relative to the corresponding percentages for disabled men: the female rate was 3.43 times the male rate for the "divorced" category, 5.92 times the male rate for the "widowed" category, and 1.05

times the male rate for the "single" category. This is a fairly consistent phenomenon for all categories of disabled persons. However, marriage (particularly maintaining a marriage) seems to be more problematic for deaf and mute women than for those in other disability categories. The 1983 statistics indicate that for deaf and mute persons, the proportion of "married" women was less than half that of men, and the "divorced" rate was 8.1 times higher for women than for men. However, in the case of mentally retarded persons, it appears that the gender differences were far smaller.

TABLE 17. PERCENTAGE DISTRIBUTION OF DEAF MUTE AND OTHER DISABLED PERSONS (AGE 13 AND ABOVE) IN JORDAN, BY SEX AND MARITAL STATUS, 1983

| Marital status | Disabled women | Disabled men | Total disabled population | Deaf and mute men | Deaf and mute women |
|---|---|---|---|---|---|
| Single | 62.17 | 59.26 | 60.30 | 67.07 | 73.20 |
| Married | 16.31 | 36.69 | 29.37 | 30.67 | 14.93 |
| Divorced | 3.36 | 0.98 | 1.83 | 0.40 | 3.23 |
| Widowed | 18.17 | 3.07 | 8.49 | 1.87 | 8.63 |

*Source*: Jordan, Department of Statistics, *Statistics on the Disabled in Jordan, 1983*, quoted from ESCWA "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

Some of the related literature has affirmed the statistical trends which reflect the problematic nature of marriage for disabled women in the countries of the ESCWA region. The following account is a prime example:

> "I then had a daughter, Sanna. When she was eight months old she had fever, and I took her to someone who gave her penicillin injections, and lo and behold, instead of recovering she became paralysed. She got polio. I stood her up on my knee one day, and suddenly her leg gave way. I was shocked. My nerves gave way. That this should happen to her and she being a girl and a woman, I knew would have grave consequences. No man would want to marry a cripple."[62]

[62] Nayra Aitya, *Khul-Khaal: Five Egyptian Women Tell Their Stories* (Cairo, American University in Cairo Press, 1988).

As the statistics show, disabled women are frequently denied many of the most basic human rights, including those related to love, marriage, and motherhood.[63] It is relatively easier for disabled men to marry, to maintain a marriage, and to fulfil family obligations and responsibilities. Arab societies, like many other societies, often fail to recognize disabled women as "women" with emotional and biological needs, desires, rights and duties. During the Regional Seminar, almost all of the disabled female participants emphasized society's failure to recognize the importance of marriage and motherhood to disabled women. The disabilities and/or appearance of these women often cause them to be rejected by society and deprived of the opportunity to enjoy the rights and privileges accorded the able-bodied (as an example, 62.17 per cent of disabled women were single in Jordan in 1983). Many parents tend to overprotect a disabled girl, discouraging her from aspiring to goals which may not be achievable in the Arab world at present.

During an interview with ESCWA staff in 1993, Ms. Heba Hagrass and Ms. Hala Awad related that they found marriage to be one of the most serious social barriers for disabled women, and shared their belief that disabled women faced more difficulty than disabled men in finding partners.

Hala Awad, who suffers from progressive muscle atrophy, emphasized that marriage for a disabled Arab woman was particularly problematic when there was some question about the genetic linkages and trends associated with a disease (such as hers), as marriage in the Arab world was mainly undertaken for the purpose of producing offspring.

In general, disabled women find it difficult both to get married and to stay married. As noted above, the gap between disabled men and disabled women appears to be narrower in cases of mental retardation. This is thought to be attributable to the fact that a man might agree to marry a mildly mentally retarded or borderline disabled woman if she is young and pretty; however, it is not easy for a mentally retarded man to marry, as men are expected to take primary responsibility for providing a secure family income.

## D. INTERVIEWS

In 1993 and 1994, ESCWA staff undertook a series of interviews with a selection of disabled Arab women for the purpose of drawing up profiles which would highlight their particular problems and circumstances. Much of what was said in these interviews reaffirms or reiterates what is written in the earlier chapters and sections of this study concerning the female-related causes of disability and the major problems

[63] See note 31.

of Arab disabled women. A summarized version of each of the interviews is provided below.

A feeling emerged from the interviews that disability was the direct result of inadequate human development in the region. There is in fact a positive correlation between poverty and fertility rates, and a negative correlation between educational level (particularly among women) and fertility rates. Further, the belief in and/or practice of family planning (one effective preventive measure against disability) correlates positively with the level of education and the quality of life. Disability is a developmental issue which for much of the population is even more closely connected with the development of women: the issues relating to disabled women—particularly the prevention of childhood disability—should be tackled within the framework of the overall advancement of women.

As noted above, very late pregnancy (particularly after age 36 or 37), a direct result of the extremely high fertility rate in Arab society, is one medical cause of childhood impairment. Some Arab States are taking practical legal measures, permitting abortion if proof exists of any serious mental or physical foetal abnormality or disability. One dimension of the problem of late pregnancy is the lack of awareness among parents and conventional medical practitioners, and another is the lack of proper facilities for perinatal medical diagnosis.

The text and table below provide a brief introduction to cases 1 and 2. Mr. and Mrs. Mailesh are a Palestinian Jordanian married couple who are originally from Hebron (West Bank).[64] In 1964, they moved to Zarqa, Jordan, because of the economic recession in Palestine. The two cases of childhood disability described below occurred within their family, but under very different circumstances and with very different outcomes. Table 18 shows how these two cases of congenital childhood disability affected the lives of two Arab mothers within the same family—one of the old generation and one of the new—and also provides an idea of how they responded to the challenges presented by these disabilities.

*Case 1: A childhood disability caused by an extremely high fertility rate (very late child-bearing), combined with the failure to have an amniocentesis test done to detect Down's syndrome*

This case features Mrs. Mailesh's stepmother, Aysha. Aysha's first husband was killed by Israeli soldiers in 1948 during the first Arab-Israeli war, as was Mrs. Mailesh's natural mother. Aysha, at 20 years of age, married Mrs. Mailesh's father, Mohammed (then aged 49). At that point, Mohammed already had seven children

[64] Mr. and Mrs. Mailesh are the landlord and landlady of the author of this study (an ESCWA staff member), and live in Um-Uthayna, an area in west Amman.

(three boys and four girls) from his first wife, including Mrs. Mailesh herself. After he married Aysha, he had another 15 children with her; 3 died and 12 survived. When Aysha delivered the last child (Abdul Aziz), she was 48 years old. Before Abdul Aziz was born, Mohammed already had 18 children of his own. Was it really necessary, then, to have a nineteenth child, to risk the occurrence of congenital mental retardation? Of course, Mohammed (whose educational attainments are limited to reading and writing) was not aware of the risk himself; neither was his wife (who is totally illiterate). It appears that, instead of seeking to practice any form of birth control, Mohammed was encouraging his 48-year-old wife to have another child. They are in the lower-middle-income bracket,[65] and regard having a lot of children as a form of security. In addition, Mohammed is very proud of his reproductive capabilities.

Aysha did not have the amniocentesis test done,[66] nor was she aware of her increased risk of bearing a disabled baby. The most depressing part of this story is that Aysha still does not understand the connection between her son's severe mental retardation (Down's syndrome) and her very late pregnancy—perhaps she will never understand it fully. This story supports the relation between an extremely high fertility rate (a very late pregnancy) and disability, and underlines the importance of "family literacy" in preventing disability. This particular case could easily have been prevented through the use of birth control, or at least discovered at an earlier stage through the amniocentesis test. Mr. Mailesh (a well-educated, self-made man)[67] hopes that this type of tragedy, common in his father's generation, will occur less frequently in the next generation, given the higher levels of education and awareness.

The only positive aspect of this story is that Aysha loves Abdul Aziz and cares as much about his welfare as that of her other children. However, the extent of Aysha's understanding of Abdul Aziz's mental disability is questionable; she simply believes that "Abdul Aziz is different from other children". Abdul Aziz went to a special primary school for mentally retarded children in Zarka for six years. His parents love him and want to send him to a vocational school; however, there is the problem of transportation, as the school is located in Russeifa (between Amman and Zarka).

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[65] Mohammed once owned his own grocery shop in Palestine, but after migrating to Jordan, he worked in construction as a stonemason.

[66] In many developed countries, this examination is mandatory for pregnant mothers over the age of 36 or 37 to detect Down's syndrome (which can cause mental retardation and physical abnormalities). The test requires that a skilled medical professional extract fluid from the pregnant mother's amniotic sac.

[67] Mr. Mailesh and Mrs. Mailesh are also cousins; however, their children are all able-bodied and well educated.

Abdul Aziz (shown in the photograph below with his mother at their home in Zarka) is now 14 years old and enjoys dancing and music.

TABLE 18. A COMPARISON OF THE DATA RELATED TO TWO CHILDHOOD DISABILITY CASES WITHIN THE MAILESH FAMILY

| | | |
|---|---|---|
| Name of the mother; residence; origin; age | Aysha; Jordan; Palestinian; 64 years old | Inam; Saudi Arabia; Palestinian; 38 years old |
| Relationship within the Mailesh family | Mrs. Mailesh's stepmother | Sister of Mr. Mailesh's son-in-law |
| Child's disability | Mental retardation (Down's syndrome) | Total blindness (two sons) |
| Cause of the childhood disability | Very late pregnancy (48 years old); failure to have an amniocentesis test done | Maternal rubella virus acquired during pregnancy; incorrect pre- and perinatal diagnoses |
| Total number of children | 15 born, but only 12 (6 boys and 6 girls) surviving | 3 boys (2 blind and 1 able-bodied) |
| Mother's level of education | Illiterate | College graduate (a two-year associate's degree and teaching credentials) from the United States of America |
| Father's level of education | Reads and writes only | College graduate (a two-year associate's degree and teaching credentials) from the United States |
| Occupation of parents; income level | Mothers is a housewife, father is a stonemason; lower-middle income | Teachers (both wife and husband); upper-middle income |
| The child's education/ training and the mother's attitude | Primary school only—now totally home-bound; loves the child | Emphasizes the need for training/rehabilitation; wishes to send the blind boys to schools in the United States; positive attitude |
| Awareness of the mother | Not aware of the cause or the need for rehabilitation; knows very little even about Down's syndrome itself | Fully aware of the risks, leading to her decision to abort |

**Abdul Aziz Mailesh and his mother, Aysha, in their home in Zarqa**

*Case 2: Congenital blindness caused by the fact that the mother was never immunized against rubella*

This account relates another disability-related tragedy in Mr. Mailesh's family. Ms. Inam Rashed Hussein, the sister of Mr. Mailesh's son-in-law, is a Palestinian-Jordanian originally from Nablus. An educated woman, she is currently living in Abha, Saudi Arabia, and working as a primary school teacher.[68] She and her husband have three sons; the eldest is unimpaired, while the two younger boys are totally blind.[69] She appears to have been infected by the rubella virus during her last two pregnancies, not having been properly vaccinated against the disease prior to either of them. As mentioned before, rubella during pregnancy is one of the major causes of congenital multiple disability (for example, blindness combined with mental retardation) in children. During her third pregnancy (after she had delivered the older blind boy), Inam went to a few hospitals for some very detailed pre- and perinatal medical exams, as she was aware of the possibility that she might still have the virus, or that it might recur. Though she was, in fact, still infected with rubella, the doctors failed to detect it; they thought she was just being overly anxious. As a result, she delivered another blind boy (her third son). Inam has some very serious misgivings about the quality of pre- and perinatal medical care in Saudi Arabia in spite of the

[68] Inam has an associate's degree in teaching from a junior college in the United States of America.

[69] So far she has not noticed any signs of mental retardation in either of her two blind boys.

state-of-the-art medical facilities and equipment available there. After bearing her three sons, she became pregnant again, but this time decided to abort the foetus, as she was too afraid of having another blind child. Inam considers herself a religious, moral woman; however, she confirms that she is guilt-free with respect to her abortion, as she believes that preventing congenital disability is the right thing to do. Regarding rehabilitation and training, Inam emphasizes the importance of "normalization" for the two blind boys, and hopes to send them to a good school in the United States where they can receive the best possible education and training. The message here is clear: the failure to follow a proper immunization programme, coupled with inadequate pre- and perinatal medical care, can add substantially to the incidence of disability in the region; every effort must be made to remedy both problems.

*Case 3: Difficulty in marriage for disabled Arab women (two cases)*

As indicated in previous sections of this study, the difficulties surrounding marriage for disabled Arab women constitute a serious barrier to their social integration; most will remain single for their entire lives. Ms. Hala Awad is a Jordanian who returned to her country from Kuwait after the Gulf crisis. She has been suffering from progressive but very mild muscular atrophy since birth. Her disability appears to be genetic, (inherited),[70] as her brother is in a wheelchair with the same disease, and two of her cousins suffer from muscular atrophy as well. While she was in Kuwait, she completed her university studies, receiving a bachelor's degree in accounting/business from a university in Beirut (through correspondence courses). Hala believes that correspondence courses provide a wealth of opportunities for physically disabled women. She is currently working at the Union Bank for Savings and Investment in Jordan. Her physical disability affects her movements only minimally—she can walk and drive—but she still faces the difficulties related to genetic disability in Jordan. The most serious problem for her is marriage. As mentioned before, marriage in the Arab world is contracted mainly for purposes of reproduction; this is particularly important in Jordan for the security of the country. Hala believes that another negative element in Jordan relates to the strong influence the parents have in the selection of a bride; marriage among Arabs is regarded as a social institution, and relatively less importance is attached to the component of mutual affection between husband and wife. Both of Hala's disabled cousins (women) are married to Westerners and reside outside Jordan; Hala expresses her intention to

[70] An occupational therapist with the King Hussein Medical Centre in Amman confirmed that the majority of patients with muscle atrophy under rehabilitation there are hereditary cases. She attributes this phenomenon to the practice of kinship marriage in Jordan.

migrate from Jordan as well, and to find a spouse who will accept her regardless of her genetic tendencies with respect to disability.[71]

Ms. Heba Hagrass, an Egyptian businesswoman with rheumatoid arthritis who is dependent on crutches and a wheelchair, confirms that there are numerous marriage problems faced by disabled Arab women. She believes that disabled Arab women have a much more serious problem than disabled men in finding marriage partners. Heba still remembers that her own parents almost gave up on her prospects for marriage, and were very annoyed when they found out that she was going to marry her cousin (her current husband). When her cousin proposed, she decided to take the risk and accept. "As [even] a number of able-bodied women are getting divorced today, why not take such a risk?" She smiles, remembering that her own father was very bewildered when she became pregnant (as Heba is "disabled"), although he congratulated her later on. Currently, she is effectively carrying out her duties as wife, mother and career woman.

*Case 4: A female war-related disability in Palestine*

Asma is a victim of the first Arab-Israeli war; her case illustrates the role armed conflict plays in female disability in the Arab world. Asma completely lost her eyesight in 1949 (during the first Arab-Israeli war), when she was one and a half years old. At that time, displaced Palestinians did not have access to proper medical care or facilities; when Asma's parents took her to a hospital, the doctor gave her the wrong prescription, and she suffered permanent loss of vision. She stresses that the aftermath of armed conflict is responsible for significant increases in the incidence of female and childhood disability, and confirms that "peace" is the most important prerequisite for reducing disability in the ESCWA region. A war itself may involve men more directly, but its aftermath has more impact on women and children, especially in the areas of medical care, nutrition, and maternity-related issues.

Asma received a diploma after completing a two-year teaching programme and is currently a Braille teacher at the Regional Centre for the Rehabilitation and Training of Blind Girls in Jordan. She went through mainstream education up to college, though she depended totally on her peers to read texts to her in high school. In college, she used a tape recorder for lectures. She singled out the lack of Braille texts as one of the main problems of visually disabled students in the region.

[71] A few months later after this interview, both Ms. Hala Awad and her disabled brother migrated to the United States.

Asma highlights two major problems of disabled women: employment and marriage. Concerning marriage, she believes that even disabled Arab men prefer to marry able-bodied women—at least partly for reasons of convenience, as they can expect assistance and care from their spouses. However, there is almost no chance for a blind Arab girl to marry an able-bodied man. The attitude of parents is another problem: there is a tendency to overprotect disabled girls. They may be closed up in the house and totally isolated from society. With respect to employment, at the school where Asma teaches, the training of telephone operators is the most successful area in terms of eventual placement. Teaching may also be considered suitable for blind women, but the lack of Braille texts poses a problem in Jordan. Recent technological developments, including the computerization of texts and the use of Braille printers and speech synthesizers, may relieve this problem somewhat in the future.

*Case 5: The important role of the family (particularly the mother) in the rehabilitation and social integration of disabled Arab women (two cases)*

As noted in chapter IV below, it is generally Arab women—mothers, sisters and daughters—who are directly involved in the care of disabled family members in the home. The role of the mother is particularly important, and her influence over the child's future development and social integration is incalculable. The importance of the mother's role in the rehabilitation and social integration of disabled girls was endorsed by all disabled women participants at the Regional Seminar.

The story of Ms. Heba Hagrass (mentioned earlier) exemplifies the validity of this concept. Heba is a successful businesswoman and fashion designer who owns two retail shops for women's clothing and accessories in Garden City, Cairo. She also actively participates in counselling disabled children's parents for an Egyptian non-governmental organization (NGO) affiliated with the Integrated Service Society. This NGO provides referral services to the parents of children with various types of disabilities; approximately 90 per cent of the clients are the parents of mentally retarded children. Heba is a wife and the mother of two children (a 13-year-old girl and an 8-year-old boy). At the age of nine years, Heba was struck with rheumatoid arthritis; since then, she has had difficulty walking, and must use either crutches or a wheelchair.

Heba received family support; most important was the unlimited support from her well-educated mother in the areas of education and training and in preparing Heba for financial independence. Heba believes that family support (particularly a mother's support) is the most important factor—in fact a prerequisite—for the integration of disabled persons in the future. Heba is most grateful for the support given to her by her own mother.

Heba's family encouraged her to attend regular (public and private) schools throughout her education. At first, her peers' reaction was negative, as she was one

of only a few disabled children at her school. She attributes this initial negative reaction, which she encounters even now on various occasions, to the image that able-bodied persons have of the disabled and particularly of disabled women, and to the tendency of human beings to base their judgements of peoples' capabilities on their first impressions. At school, however, as Heba demonstrated and convinced others of her capabilities, and as her academic performance proved outstanding, her peers gradually started accepting her. During her adolescence, when she encountered emotional and social problems as a young disabled Arab woman, her mother always emphasized her capabilities, creativity and excellent qualities, and stressed the importance of self-confidence and self-esteem. Later, she obtained a bachelor's degree in business administration from the American University in Cairo.

Heba attributes her success and achievements to her mother's support during her childhood and adolescence. She thinks that family background and the parents' level of education and social class are all important, as these factors tend to determine the value system. However, she emphasizes that a high educational level *per se* is not sufficient unless it is accompanied by "genuine understanding", as she has come into contact with so many well-educated parents who do not know how to cope with their disabled children, and who tend to perceive a disabled child as a failure.

Heba highlights the following as the major problems affecting disabled women in Egypt:

(a) Physical restrictions on mobility in public (which prevent disabled women from actively participating in daily activities) and poorly designed and maintained infrastructural facilities (public transportation, buildings, sidewalks and so on);

(b) A negative image of disabled persons, and particularly of disabled women;

(c) Marriage-related difficulties and the mythical image of the oversexed disabled woman;

(d) A negative self-image and lack of self-esteem among disabled women.

Ms. Munira Bin Hindi of Bahrain, another successful disabled woman, confirms the importance of the mother. Munira is President of the Bahrain Centre for International Mobility, a social worker/counsellor for disabled persons and their families in the Social Rehabilitation Section of the Ministry of Labour and Social Affairs, a member of the Bahrain National Committee for Disabled Persons,[71] a

[71] Munira Bin Hindi is the only disabled member of the Bahrain National Committee for Disabled Persons, and is one of six females on the Committee (composed of 13 members).

member of the Bahrain National Committee for the International Year of the Family (IYF), and a businesswoman.

At the age of one and a half, Munira caught poliomyelitis, and since that time has been confined to a wheelchair. She has received plenty of family support—particularly from her mother (who is illiterate) in the areas of early intervention and rehabilitation, education and training. Immediately after contracting poliomyelitis, she was sent to India for six months for physiotherapy and other training. Her father died when she was 10 years old. Munira believes that family support is the most important factor in the integration of disabled persons; she agrees that the role of the mother is of particular importance, and is most grateful for the support given to her by her own mother.

Munira's mother encouraged her to attend a regular (public) school throughout her education. At first, her peers' reaction was not very positive, as she was the only disabled child at her school. Soon, however, she distinguished herself through her outstanding academic performance, and her peers started accepting her and respecting her academic achievement and creativity; she was active not only in academic pursuits, but also in acting, poetry composition, school broadcasting, and other extracurricular activities.

Munira sometimes encountered negative attitudes from her peers and teachers, and was forced to overcome the social barriers they created. For instance, when she wanted to join Girl Scouts, her teacher told her to forget the idea, as she would not be able to fully participate in the activities and the uniform would not fit her. However, she insisted on her normalization, and her classmates finally supported her and helped her convince her ignorant teacher that she could manage.

Munira later completed her education, obtaining a degree in psychology from Cairo University. She has participated in a number of disability-related fellowship programmes in the United States of America, Canada, the United Kingdom of Great Britain and Northern Ireland, Austria, Egypt, Kuwait, and other countries.

At present, Munira is very active in promoting "accessibility"—namely, barrier-free architecture and transportation for disabled citizens in Bahrain—in her capacity as the President of the Bahrain Centre for International Mobility. She is working hard to get new regulations for barrier-free design passed in Bahrain.

Munira believes that it is her strong will and determination that have enabled her to achieve success in spite of her disability and gender. She encourages other disabled women to work hard at building their self-esteem and confidence: "You must have confidence in yourself before society can have confidence in you". Munira is also very pragmatic, however, she strongly believes that family wealth and financial support is a prerequisite for achievement among disabled female children in Bahrain.

Also active in her private life, Munira is currently involved in writing an autobiography, composing poems, and collecting Bahraini proverbs; for the last project, she is visiting various villages on the island with the help of her mother. She has also recently opened her own shop for women's accessories. She believes that such retail businesses are good for disabled women, as some of them have a wide range of contacts, and their friends may wish to patronize the shops.

Disabled persons are almost exclusively cared for by women in many parts of the world. Family care (for dependants) has become increasingly preferred all over the world for a number of practical and financial reasons (such as the world recession). In the countries of the ESCWA region, the great majority of family care-givers are women. Arab society takes it for granted that caring for disabled family members, children and the elderly is a family responsibility—one that falls mainly to women. However, Arab women also contribute significantly to the disability-related services provided in the public sector (rehabilitation centres, institutions, special education and so on) in both professional and supporting capacities.

# IV. THE ROLE OF WOMEN IN THE FORMAL SETTING IN JORDAN AND BAHRAIN

Arab women play a significant role in the formal institutional setting for the rehabilitation and social integration of disabled persons.

## VISITS OF ESCWA STAFF TO THE REHABILITATION SERVICE CENTRES, AND INTERVIEWS WITH ARAB WOMEN WORKING WITH DISABLED PERSONS

Having covered the major causes of impairment and some of the problems related to disabled women, the focus of this study now shifts to an investigation of the services provided for disabled women and to the role women play in providing "public" services. To this end, field visits were made to various facilities in two countries (Jordan and Bahrain), and some interviews with professional Arab women working in the field were carried out. The present chapter focuses on the contribution of professional Arab women within the more formal service settings, including centres affiliated with NGOs and public institutions; the role of women as care-givers in the informal setting will be discussed in detail in chapter V.

### *1. Services for disabled persons and the role of women in Jordan*

It is worth mentioning that the person in charge of the delivery of services for disabled persons at the Ministry of Social Development in Jordan is a woman; Ms. Amal Nahas is the Director of the Ministry's Department of Special Education. Amal

obtained a bachelor's degree in psychology and a master's degree in special education for mentally retarded persons at the University of Jordan, where she also completed an intensive training course for educating the deaf. After finishing her bachelor's degree, she worked as a regular schoolteacher for three years, gradually coming to the realization that some of the students enrolled in regular schools required additional assistance and a special curriculum.

Amal's current responsibilities include supervising the operation of all public special education schools and social rehabilitation centres in the country. She is also responsible for the development of programmes and budgets in accordance with the urgent needs of these facilities. Further, she provides consultative and referral services to parents of disabled children and organizes training courses and meetings for special education teachers and other professional staff.

There are a total of 30 governmental rehabilitation facilities in Jordan: 1 for the blind, 11 for the deaf, 1 for the physically handicapped, 10 for mentally retarded persons, 1 for those with multiple disabilities, 3 for other handicapped groups, and 3 for vocational rehabilitation and training. Nearly the same number of rehabilitation facilities (a total of 31) are run by non-governmental and voluntary societies, broken down as follows: 2 for the blind, 4 for the deaf, 1 for the physically handicapped, 15 for mentally retarded persons, 1 for those with multiple handicaps, 1 for other handicapped groups, and 7 for vocational rehabilitation.

Amal believes that the most serious problems confronting disabled women in Jordan parallel those faced by women in general; these include the lower priority given to girls and women by the family in all areas and aspects of life, a higher illiteracy rate, lower enrolment ratios in higher education, the lack of access to various services, and the fact that they generally receive an unequal share of benefits. She emphasized the necessity of tackling women's disability issues within the overall framework of Jordanian women's advancement and development. According to her, the social barriers created by traditional values and the lack of access to specialized services are among the major problems of disabled women in particular. She strongly believes that the concept of "independent living" should be gradually introduced and applied (in an appropriately modified form) to the next generation of disabled women in Jordan, in a manner consistent with the country's cultural patterns and dynamic value systems. A group of disabled women living within a self-help cooperative (or a similar type of arrangement), with active community support, would constitute a good initial challenge. Another important point should be reiterated here: because the training of disabled women is given such low priority, there should be a direct incentive such as gearing the training towards immediate opportunities for income generation upon completion of the training programme in order to invite the support and cooperation of the family.

(a) Regional Centre for the Rehabilitation and Training of Blind Girls

Jordan has one governmental and two non-governmental institutions for the blind; one of the latter is the Regional Centre for the Rehabilitation and Training of Blind Girls, a facility run by a female Jordanian specialist. Ninety-five per cent of the Centre's funding is provided by the Regional Bureau of the Middle East Committee for the Affairs of the Blind (located in Riyadh), and 5 per cent by the Jordanian Government. The Centre is currently providing training and rehabilitation services for 36 blind girls and women aged 15 to 35. The head of the Centre, Ms. Hala Jawhari, was formerly employed as a teacher in Saudi Arabia; her academic background is in education and psychology. Except for the resident medical doctor, the Centre's entire staff is made up of women—including a special education teacher, a physical education teacher, four handicrafts teachers, a music teacher, a Braille teacher, a mobility trainer/maths teacher, a librarian, some nurses, and some telephone switchboard operators who are graduates of this Centre. The Centre also has boarding facilities for resident students which are run entirely by Jordanian women.

(b) Young Muslim Women's Association (YMWA) Centre for Special Education

Another NGO run by a female specialist in Amman is the YMWA Centre for Special Education. Located in a suburb of Amman, the Centre is a voluntary organization offering its services to mentally retarded boys and girls aged 3 to 18, and includes preschool, school, and vocational training sections, as well as an attached sheltered workshop. The activities of this Centre constitute a good example of parent and community involvement. Those at the Centre believe that parental involvement in the education of a child is crucial to the comprehensive development of the individual; therefore, the Centre hosts an open day for parents once a week. Parents can use the time to observe their children in the classroom and consult with teachers regarding their children's progress. Parents of the first-year preschool students and of children with severe behavioural problems are invited to attend the classes for a minimum of one day per month. The Centre has also established a parent-teacher association (PTA), which aims at providing informative programmes on issues related to the children and at organizing fund-raising activities.

The Centre provides various services to the community as well; it has, for example, participated in a literacy programme for the Bunayat area, and has organized an "open day" programme for any parents in the community who might need counselling or referral services. The Director of the Centre, Ms. Ghusoon Kareh,[72] participated in the development of *A Parent Guide to Dealing with Mentally*

[72] Ms. Ghusoon Kareh also contributed to efforts leading to the enactment of the 1993 Law on the Handicapped in Jordan.

*Handicapped Children*, published under the auspices of the United Nations Children's Fund (UNICEF) and the Queen Alia Jordanian Social Welfare Fund.[73]

### 2. *Services for disabled women and the role of women in Bahrain*

First, it is worth noting that the Director of the Social Rehabilitation Section within the Ministry of Labour and Social Affairs is a woman, Ms. Hanan Kamal. Hanan is in charge of social rehabilitation for disabled persons in Bahrain, and is also the Vice-President of the Bahrain National Committee for Disabled Persons.

#### (a) Al-Amal School for Disabled Children of the Association for the Welfare of Children and Mothers

In Bahrain, there are a number of centres for disabled persons run by NGOs. Al-Amal School for Disabled Children of the Association for the Welfare of Children and Mothers, a voluntary association of Bahraini women located in the town of Issa, was established in 1982 (having previously been known as Al-Amal House School, founded in 1977). The change in name and focus was a direct response to the urgent need for services in the field of special education; it also reflects the importance that the Association for the Welfare of Children and Mothers attaches to providing services for disabled children. The School has units for curriculum development and research, special education, pre-vocational training, evaluation and diagnosis, and staff training. During the visit of an ESCWA staff member in 1993, the School was offering services to 131 mildly mentally retarded children (61 boys and 70 girls, 126 of them Bahraini and 5 from other Arab countries).

The School's curriculum development and research unit offers a special education curriculum which was developed in Jordan and is geared towards providing an Individually Designed Instructional Educational Programme (IDIEP) for each mildly handicapped student. The unit has also developed a Bahraini version of the American Association of Mental Deficiency Adaptive Behavior Scale for use in all special education schools. Curriculum development is supervised by the Ministry of Education.

Within the special education unit, the aforementioned curriculum is offered to mildly mentally retarded children (those within the intelligence quotient [IQ] range of 50 to 70) between the ages of 6 and 15. The pre-vocational unit conducts several training courses which are particularly geared towards girls, offering them instruction in sewing, cooking, home economics and daily living skills.

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[73] Much of this section is derived from an article entitled "YMWA marks 20 years of service to the disabled", *Jordan Times* (11 October 1994).

It is worth noting that the Director of this School is a woman, and that out of 14 special education teachers, 13 are women (1993 statistics). The teachers studied at the Arabian Gulf University, which offers a graduate-level programme in special education, as well as an advanced diploma programme in special education for regular teachers.

(b) The Children's Rehabilitation Home

In 1970 the Ministry of Labour and Social Affairs set up the Children's Rehabilitation Home (prior to the establishment of Al-Amal School, mentioned above. The Home provides free services for children between the ages of 6 and 17 suffering from severe mental and/or physical disabilities. Today, the Home caters to young people whose more serious disabilities preclude them from being admitted to Al-Amal School—more specifically, those who are afflicted with cerebral palsy, Down's syndrome or autism, and/or are severely mentally retarded. The Home includes a permanent residential care unit, a day-care unit and a physiotherapy unit. This is a place for severely disabled individuals where governmental services are provided free of charge; as might be expected, the facilities are not in totally satisfactory condition.

During the visit of an ESCWA staff member in 1993, the permanent residential care unit was accommodating 22 severely disabled young people (5 males and 17 females) whose families were either unable or unwilling to take care of them.

The Home also offers short-term residential care to children who need temporary shelter when their families are travelling abroad and cannot care for them properly. Day care is provided within the same unit for commuting students. During the 1993 visit, this unit was providing services for 131 students (62 girls and 69 boys). Last is the physiotherapy unit, which was providing services to 13 students during the 1993 visit; the two certified physiotherapists working there are both women.

The services provided by the Home include medical and health examinations, the treatment of illness, psychological treatment, education, rehabilitation, physiotherapy and recreation. Because of the severity of the children's disabilities, the Home employs a large staff; 52 of the 59 employees are women, including the Director of the Home and the special education teachers, physiotherapists, social workers, nurses, care-givers, secretaries and other administrative staff.[74] The few men working at the Home are either drivers or manual labourers. According to the Director, working conditions are very tough; there is a shift system, as the Home is operational 24 hours a day.

[74] In Bahrain, most of the care-givers who are directly responsible for disabled persons at residential centres are women; the working conditions and financial incentives may not be sufficient to attract men.

All of the Home's services are offered free of charge. However, after reaching the age limit (17), each child must leave the Home. This is problematic, as most of the graduates are too severely handicapped to join Al-Amal School's pre-vocational rehabilitation or special education unit. In concluding this subsection, it is worth noting that the role played by Bahraini women here is more "significant"; it can even be concluded that this Home is run entirely by a team of such women.

(c) Bahrain Centre for International Mobility

The Bahrain Centre for International Mobility, an NGO founded in 1979, works at removing physical barriers and facilitating the transportation and movement of disabled citizens in Bahrain. It also facilitates the participation of disabled persons in cultural exchange programmmes at the local, regional and international levels.

The Centre has an elected Board of Directors consisting of disabled members and volunteers. The Chairman of the Board and President of the Centre is a physically disabled woman, Ms. Munira Bin Hindi (the subject of case-study 5 in chapter III). According to her, there are a number of successful disabled women in the Arab region, but there are very few disabled women who are heads of organizations. Munira is also a member of the Bahrain National Committee for Disabled Persons, whose objectives and tasks include drawing up general policies for the rehabilitation of the disabled, proposing and introducing legislation, preparing studies, and implementing preventive schemes in accordance with the World Programme of Action concerning Disabled Persons after the end of the United Nations Decade of Disabled Persons (1983-1992). Within the institutional frameworks of both the Committee and the Bahrain Centre for International Mobility, Munira is working hard to promote the development and enactment of new legislation which would guarantee free access for disabled citizens and set barrier-free architectural requirements.

## V. THE ROLE OF WOMEN IN THE INFORMAL SETTING

The role of women is very important in the areas of impairment prevention, early intervention and medical treatment, rehabilitation, and social integration. Theoretically, women should not be the only ones responsible for dealing with the challenges of disability; the care of disabled persons should be a cooperative effort shared by all members of society. However, in the Arab world, society supports the role of women as care-givers, and many women are proud of being able to assume responsibility for the care of a disabled family member. Within this context, Arab women generally end up providing the bulk of both informal and public services for disabled persons.

In the area of disability prevention, women play an extremely significant role. An impairment or disability involves costs which must be borne not only by the disabled person, but also by his or her family and community—and ultimately by the State; it

therefore stands to reason that investing in prevention is the wisest course to follow. The mother's role is vital in this area. Arab women should be educated and informed about the importance of both appropriate birth spacing and physical recovery between pregnancies, and should be encouraged to breast-feed as much as possible, especially during the child's first few months. Arab women should also be made aware of the possible consequences of kinship marriage; young, unmarried women should be encouraged to assert themselves in this regard to contribute towards preventing the worst possible congenital cases. Public nurses, community-health workers and birth attendants play an essential role in primary health care programmes, as they are trained to detect a number of disorders which are curable if treated at the early stages, but which may cause permanent disability if timely intervention is not undertaken. Preventive measures should be developed within the framework of the overall development of Arab women. For instance, with regard to one of the major contributing factors to severe disability in the ESCWA region, many experimental studies have indicated that female education is more effective than male education in lowering the rates of kinship marriage. The training and education of women (especially mothers) also have a significant impact on their ability to detect symptoms. During an interview with ESCWA staff, the mother of Hala Awad said that she had noticed abnormality in her son's development six months after his birth.[75] Although a number of doctors (general practitioners) in Kuwait failed to diagnose her son's symptoms, she continued observing his abnormal movements and insisted that something was wrong; finally, a specialist concurred, and diagnosed the illness as muscular atrophy. Both Hala and her disabled brother expressed their appreciation for the support, dedication and affection given to them by their mother during their upbringing.

As mentioned repeatedly in this study, it is generally the women in the Arab world who are directly involved in the treatment, rehabilitation and care of disabled persons, whether at home or in institutions; at home, it is usually the mother, sister or daughter who cares for a disabled relative. In addition, with all of the Arab women interviewed for this study confirming that marriage is much easier for disabled Arab men, it appears quite likely that a great many single disabled women may have to take care of themselves after their parents die. Taking these circumstances into consideration, it seems appropriate to conclude that priority for training should be given to women. Community-based rehabilitation (CBR) should be encouraged, as this approach offers greater advantages in terms of both the costs involved and the utilization of available human resources.

Finally, it should be emphasized once again that responsibility for the disabled should be shared among all family members—supplemented by professional guidance

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[75] Hala's elder brother had also realized by that point that something was wrong with the boy.

and financial and moral support where available—so that Arab women do not have to shoulder the burden of family care alone.[76]

The following comprises those recommendations of the Regional Seminar that concern the role of the family or certain of its members.

1. The importance of the family's role in preventing childhood disability should be emphasized. Literacy and the overall development of Arab family members—especially that of women and mothers—should be encouraged, as these factors constitute prerequisites for early intervention and the prevention of disability in the region.

2. Families should keep abreast of new developments related to the treatment of disability and should make use of new methods and appropriate technologies.

3. Proper birth spacing should be practised, and very early and very late pregnancies should be avoided.

4. Breast-feeding and proper weaning practices should be encouraged, and both mothers and children should have a balanced diet.

5. Health authorities should assume responsibility for the primary health care of mothers and children, providing the necessary immunizations and appropriate pre-, peri-, and postnatal care, but also concerning themselves with the prevention and early detection of disability and early intervention. Primary health care should also be directed towards the treatment of disabling conditions and should involve careful monitoring of the validity of vaccines. It should be stressed that the family plays a significant role in ensuring the implementation of an effective primary health care programme.

6. Unhealthy or dangerous practices such as smoking, the use of drugs and alcohol, and exposure to X-rays should be avoided during pregnancy.

7. The family's role in helping a disabled child to overcome psychological barriers should be recognized.

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[76] Separate ESCWA documents on the role of the family (particularly mothers) in caring for the disabled are also available. These include: "Women and disability: the role of the family" (E/ESCWA/SD/1994/WG.1/7); "Childhood disability: causes and role of family in prevention, early detection and rehabilitation" (E/ESCWA/SD/1994/WG.1/6); and "The role of the family and popular action associations in disability prevention, early detection and rehabilitation in Lebanon" (E/ESCWA/SD/1994/WG.1/5 [in English and Arabic]).

8. Families should involve their disabled children in family and community activities.

9. Appropriate technical, moral and financial support, including family counselling, should be provided where possible to families caring for disabled members; such support should be offered from the beginning (when the disability first occurs or is first diagnosed).

10. Rehabilitation institutions and centres for disabled persons should work together with the family in order to ensure the fullest integration of disabled persons (especially women).

11. Family-support programmes should be instituted which provide short-term relief for families with disabled children.

12. Economic support should be provided by Governments to the families of disabled persons as a means of providing some relief in the home (for example, to facilitate the employment of a helper or maid).

13. Free, compulsory education should be made available for all children, including those that are disabled.

14. The family and the community should promote the integration of disabled persons in recreation programmes.

## VI. CONCLUSION AND RECOMMENDATIONS

The present study finds that in most countries of the ESCWA region, women do not have access to the same resources and opportunities available to men. Many disabled Arab citizens and regional experts believe that the World Programme of Action concerning Disabled Persons failed to achieve its objectives during the United Nations Decade of Disabled Persons (1983-1992). It is widely recognized that a new set of long-term strategies is needed to sustain efforts to achieve the objectives of the World Programme of Action in the ESCWA region, particularly with respect to the more disadvantaged group—women—of the most disadvantaged population group—the disabled.

ESCWA has organized a number of forums for discussion, including the Conference on the Capabilities and Needs of Disabled Persons in the ESCWA Region (held in Amman from 20 to 28 November 1989), the Cultural Event for Disabled Persons in the ESCWA Region: An Event to Mark the End of the United Nations Decade of Disabled Persons (1983-1992) in the ESCWA Region (held in Amman on

17 and 18 October 1992), and the ESCWA Regional Seminar on the Role of the Family in Integrating Disabled Women into Society (also held in Amman, from 16 to 18 October 1994). All of these meetings singled out disabled women as the most disadvantaged group, and recognized the need to provide them with special attention. The findings of this study, which are based on available statistics and interviews, have empirically supported the recommendations of the three meetings.

The following suggestions are based on the recommendations of the above-mentioned meetings, on the results of this study, and on comments made by disabled Arab individuals and their families. The suggestions are not absolute, as they need to be adapted and modified in accordance with the conditions in each country and each community of the ESCWA region and with the rapid social and technological change in the area.

1. Disabled women in the ESCWA region have the same problems as disabled men; however, many of these difficulties are compounded for disabled women, and there are characteristics of these problems which apply only to them. Among other things, disabled Arab women's participation in education, training and employment is very limited compared with that of disabled men and able-bodied women—a circumstance which is attributable to the position of Arab women in general. The issues relating to disabled women should be dealt with within the overall framework of women's development in the Arab world. In particular, the mainstreaming of disabled Arab women in education, training and employment should be promoted.

2. Although the majority of disabled Arab women are not formally employed, a number of them are engaged in home-based or other such income-generating activities. The contributions made by disabled women in the informal sector should be recognized. Concerned institutions should develop programmes to train disabled women to perform various types of home-based income-generating tasks, and should also provide them with the necessary aid for that purpose. It is also necessary to facilitate the means for adapting the physical environment inside the home to the needs of disabled women. Finally, it is vital that disabled women be offered psychological counselling and practical training that will enable them to take better care of themselves and their children.

3. In the Arab world, disabled women face more discrimination and difficulty in marriage than do disabled men. As a substantial proportion of disabled Arab women are single, widowed or divorced, appropriate marriage counselling services should be provided for them. Further, efforts should be made to change negative public opinion regarding marriage for or to disabled women.

4. The importance of the role of women and mothers in preventing childhood disability should be emphasized; particular stress should be placed on community-based rehabilitation. The statistical data in this study affirm that there is a significant

correlation between the mother's illiteracy and the incidence of childhood disability. Literacy among Arab women and their overall development constitute prerequisites for effective disability prevention and early intervention efforts in the region. Efforts should also be made to deal with other causes of disability such as poverty, malnutrition, traffic accidents, home accidents and armed conflicts.

5. It is clear from the census data that disabled women are under-enumerated—a manifestation of prevailing negative social attitudes. Another, related problem is that the available literature on this subject is limited. Public awareness of the capabilities and needs of disabled women should be boosted, and every effort should be made to facilitate and promote their social integration. Practical efforts should concentrate on the rehabilitation of disabled women and on breaking down social barriers that stand in the way of both their active participation in economic life and their fulfilment in private and public life.

6. Kinship marriage, a prevailing practice in the ESCWA region, is a negative socio-cultural factor affecting the incidence of hereditary disability. It is important to alert the public about the dangers and possible consequences of intermarriage among close relatives. As a related issue, women's education should be given more attention, as it has been shown to have more of an impact than men's education on discouraging kinship marriage and other detrimental practices. Proper genetic counselling should also be made available to couples.

7. Arab women play a significant role in the formal setting; some rehabilitation centres are run entirely by these women. Rehabilitation in the institutional setting should be recognized as a field which can absorb many well-qualified and well-educated Arab female labour-force candidates.

8. A number of new technologies (computer-based Braille and computer synthesizers), items (large-print texts), and fields (informatics), as well as the adaptation of the physical environment (through barrier-free design), greatly enrich the lives of disabled persons and should be promoted as powerful instruments which facilitate the fullest possible integration of disabled Arabs—especially women—in daily life.

9. All national, regional and international programmes and projects for the advancement of women should be designed to accommodate the needs of disabled women as well.

## Annex

# DISABILITY-RELATED TABLES FOR SELECTED COUNTRIES IN THE ESCWA REGION

ANNEX TABLE 1. BASIC INDICATORS FOR THE ESCWA REGION

| | Mortality rate for children under age 5 (per 1,000) | | | Infant mortality rate (per 1,000) | | | Total population (thousands) | | GNP per capita (US dollars) | | Life expectancy at birth | | Adult literacy rate (percentage) | | Total fertility rate (per woman) | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1960 | 1990 | 1992 | 1960 | 1990 | 1992 | 1990 | 1992 | 1989 | 1991 | 1990 | 1992 | 1970 M/F | 1990 M/F | 1990 | 1992 |
| Bahrain | 208 | 17 | 16 | 130 | 14 | 13 | 516 | 533 | 6 360 | 7 130 | 71 | 71 | .. | .. | .. | .. |
| Egypt | 301 | 85 | 55 | 179 | 61 | 55 | 52 400 | 54 800 | 640 | 610 | 60 | 61 | 50/20 | 63/34 | 4.3 | 4.2 |
| Iraq | 222 | 86 | 80 | 139 | 63 | 64 | 18 900 | 19 300 | 2 340 | 1 500 | 65 | 66 | 50/18 | 70/49 | 6.1 | 5.7 |
| Jordan | 217 | 52 | 30 | 135 | 40 | 25 | 4 000 | 4 300 | 1 640 | 1 050 | 67 | 68 | 64/29 | 89/70 | 5.8 | 5.7 |
| Kuwait | 128 | 19 | 17 | 89 | 17 | 17 | 2 000 | 2 000 | 16 150 | 16 150 | 73 | 75 | 65/42 | 77/67 | 3.7 | 3.7 |
| Lebanon | 91 | 56 | 44 | 68 | 44 | 35 | 2 700 | 2 800 | 2 150 | 2 150 | 66 | 68 | 79/58 | 88/73 | 3.6 | 3.1 |
| Oman | 378 | 49 | 31 | 214 | 37 | 24 | 1 500 | 1 600 | 5 220 | 6 120 | 66 | 69 | .. | .. | 7.1 | 6.8 |
| Qatar | 239 | 36 | 33 | 145 | 29 | 27 | 368 | 453 | 15 500 | 14 770 | 69 | 70 | .. | .. | .. | .. |
| Saudi Arabia | 292 | 91 | 40 | 170 | 65 | 35 | 14 100 | 15 900 | 6 020 | 7 820 | 65 | 69 | 15/2 | 73/48 | 7.1 | 6.4 |
| Syrian Arab Republic | 217 | 59 | 40 | 135 | 44 | 34 | 12 500 | 13 300 | 980 | 1 160 | 66 | 67 | 60/20 | 78/51 | 6.5 | 6.2 |
| United Arab Emirates | 289 | 30 | 22 | 145 | 24 | 18 | 1 600 | 1 700 | 18 430 | 19 860 | 70 | 71 | 24/7 | 58/38 | 4.6 | 4.5 |
| Yemen | 378 | 187 | 177 | 214 | 114 | 107 | 11 700 | 12 500 | 650 | 520 | 51 | 52 | 14/3 | 47/21 | 7.7 | 7.2 |

*Sources*: United Nations Children's Fund (UNICEF), *The State of the World's Children 1992* (New York, Oxford University Press, 1992); and *The State of the World's Children 1994* (New York, Oxford University Press, 1994).

ANNEX TABLE 2. INDICATORS RELATED TO WOMEN AND DISABILITY IN THE ESCWA REGION

| | Life expectancy for females as a percentage of males | | Adult literacy rate: females as a percentage of males | Percentage of pregnant mothers immunized against tetanus | | Maternal mortality rate (per 100,000) | | Percentage of children underweight (0-4 years) | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | 1980-1991 | | 1980-1992* | |
| | 1990 | 1992* | 1990 | 1989-1990 | 1990-1992* | 1980-1990 | 1980-1991* | Moderate/ severe | Severe | Moderate/ severe | Severe |
| Bahrain | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. |
| Egypt | 105.1 | 104 | 54 | 63 | 70 | 320 | 270 | 13 | 3 | 10 | 3 |
| Iraq | 103.1 | 105 | 70 | 67 | 45 | 120 | 120 | .. | .. | 12 | 2 |
| Jordan | 106.2 | 106 | 79 | 23 | 32 | 48 | 48 | .. | .. | 6 | 1 |
| Kuwait | 105.6 | 106 | 87 | 22 | 22 | 6 | 6 | 6 | .. | 6 | .. |
| Lebanon | 106.3 | 106 | 83 | .. | .. | .. | .. | .. | .. | .. | .. |
| Oman | 106.3 | 106 | .. | 97 | 97 | .. | .. | .. | .. | 23 | 5 |
| Qatar | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. |
| Saudi Arabia | 104.8 | 104 | 66 | 62 | 62 | .. | 41 | .. | .. | .. | .. |
| Syrian Arab Republic | 106.3 | 106 | 65 | 84 | 63 | 140 | 140 | .. | .. | .. | .. |
| United Arab Emirates | 107.2 | 106 | 66 | .. | .. | .. | .. | .. | .. | .. | .. |
| Yemen | 102.9 | 102 | 49* | 8 | 13 | .. | .. | 53 | .. | 30 | 4 |

ANNEX TABLE 2. *(continued)*

| | Percentage of one-year-old children fully immunized against poliomyelitis | | | Percentage of mothers breast-feeding, 1980-1991 | | | Percentage of children (1986-1992)* who were: | | | Percentage of births attended by trained health personnel | | Secondary school enrolment ratios 1986-1991 (percentage) | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1981 | 1989-1990 | 1990-1992* | 3 months | 6 months | 12 months | Exclusively breast-fed (0-3 months) | Breast-fed with complementary food (6-9 months) | Still breast-feeding (20-23 months) | 1983-1990 | 1983-1992* | Male | Female |
| Bahrain | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. |
| Egypt | 84 | 87 | 89 | 90 | 83 | 68 | 38 | 52 | .. | 47 | 41 | 92 | 71 |
| Iraq | 16 | 75 | 64 | 76 | 45 | 19 | .. | .. | .. | 50 | 50 | 58 | 37 |
| Jordan | 87 | 92 | 97 | 93 | 80 | 61 | 32 | 48 | 13 | 83 | 87 | 79 | 73 |
| Kuwait | 76 | 94 | 92 | 47 | 32 | 12 | .. | .. | .. | 99 | 99 | 93 | 87 |
| Lebanon | .. | 82 | 85 | 50 | 40 | 15 | .. | .. | .. | .. | 45 | 57 | 56 |
| Oman | 9 | 96 | 97 | 75 | 55 | 20 | .. | .. | .. | 60 | 60 | 59 | 48 |
| Qatar | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. |
| Saudi Arabia | 52 | 94 | 96 | 91 | 52 | .. | .. | .. | .. | 88 | 90 | 55 | 41 |
| Syrian Arab Republic | 14 | 90 | 89 | 81 | 72 | .. | .. | .. | .. | 61 | 61 | 60 | 43 |
| United Arab Emirates | 45 | 85 | 86 | .. | .. | .. | .. | .. | 26 | 99 | 99 | 63 | 72 |
| Yemen | 21 | 53 | 62 | 74 | 66 | 34 | 15 | 51 | .. | 12 | 16 | 47 | 10 |

*Sources*: United Nations Children's Fund (UNICEF), *The State of the World's Children 1992* (New York, Oxford University Press, 1992); and *UNICEF, *The State of the World's Children 1994* (New York, Oxford University Press, 1994).

ANNEX TABLE 3. PERCENTAGE OF MALES AND FEMALES CURRENTLY MARRIED IN SELECTED COUNTRIES OF THE ESCWA REGION, BY AGE GROUP AND SEX, LATEST AVAILABLE YEAR

| Country | Year | Percentage currently married in the age group 15-19 | | | Percentage currently married in the age group 20-24 | | | Percentage currently married in the age group 25-44 | | | Percentage currently married in the age group 45-59 | | | Percentage currently married in the 60-plus age group | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Males | Female | Total | Males | Female | Total | Males | Female | Total | Males | Females | Total | Males | Females | Total |
| Bahrain | 1989 | 0.23 | 5.48 | 2.82 | 8.40 | 35.31 | 21.50 | 69.36 | 61.42 | 65.26 | 93.71 | 71.56 | 82.43 | 85.50 | 36.18 | 63.08 |
| Egypt | 1986 | 3.39 | 16.67 | 9.61 | 17.15 | 58.32 | 36.79 | 79.64 | 85.88 | 82.78 | 94.64 | 68.26 | 81.50 | 85.11 | 28.42 | 57.40 |
| Iraq | 1987 | 5.77 | 19.97 | 12.58 | 27.24 | 53.36 | 39.53 | 78.27 | 82.11 | 80.12 | 94.84 | 77.21 | 86.29 | 88.60 | 50.03 | 68.23 |
| Jordan | 1991 | 0.58 | 8.86 | 4.55 | 11.63 | 39.68 | 24.89 | 74.40 | 81.59 | 77.99 | 98.42 | 82.77 | 90.97 | 92.74 | 47.56 | 72.94 |
| Kuwait | 1988 | 0.62 | 8.90 | 4.79 | 19.23 | 42.57 | 31.79 | 84.28 | 82.30 | 83.48 | 98.46 | 79.11 | 92.02 | 93.12 | 32.64 | 67.97 |
| Lebanon | 1970 | 1.01 | 12.91 | 6.82 | 11.76 | 48.44 | 29.72 | 72.65 | 81.20 | 76.95 | 91.41 | 76.33 | 84.08 | 85.67 | 45.08 | 65.69 |
| Oman | 1988-1989 | 3.83 | 36.00 | 20.42 | 37.45 | 83.66 | 63.21 | 80.98 | 75.11 | 78.39 | 93.10 | 73.84 | 84.08 | 83.71 | 29.20 | 61.87 |
| Qatar | 1987 | 3.44 | 14.09 | 8.28 | 25.04 | 58.24 | 35.69 | 78.11 | 83.37 | 79.34 | 95.96 | 75.13 | 91.01 | 92.56 | 34.27 | 70.13 |
| Saudi Arabia | 1974 | 5.68 | 40.64 | 21.73 | 31.64 | 78.66 | 51.81 | 79.60 | 89.25 | 84.06 | 90.78 | 69.07 | 81.60 | 82.50 | 27.78 | 58.62 |
| Syrian Arab Republic | 1981 | 3.77 | 24.55 | 13.85 | 25.14 | 63.50 | 44.05 | 84.13 | 87.54 | 85.83 | 96.65 | 82.52 | 89.83 | 88.55 | 49.56 | 69.70 |
| United Arab Emirates | 1987 | 2.18 | 17.39 | 9.87 | 26.13 | 49.30 | 39.23 | 83.32 | 79.12 | 80.93 | 95.33 | 65.91 | 81.08 | 86.21 | 29.12 | 60.21 |

*Sources*: Bahrain, Ministry of Health, *Bahrain Child Health Survey, 1989*; Egypt, Central Agency for Public Mobilization and Statistics, *Population Census, Final Results, 1986*, Population Characteristics, Total Republic; Iraq, Central Statistical Organization, *Population Census Results*, Total Republic, 1987; Jordan, Department of Statistics, *Labour-force, Unemployment, Returnees and Poverty, 1991*; Kuwait, Central Statistical Office, *Final Results of Labour-force Sample Survey, 1988*; Lebanon, Central Bureau of Statistics, *Labour-force Survey in Lebanon, Demographic Characteristics 1970*; Oman, Ministry of Health, *Oman Child Health Survey, 1988-1989*; Qatar, Central Statistical Organization, *Population and Housing Census, 1987*; Saudi Arabia, Central Department of Statistics, *General Population Census, Detailed Results*, 1974; Syrian Arab Republic, Office of the Prime Minister, Central Bureau of Statistics, *Population Census of the Syrian Arab Republic, 1981*; and the United Arab Emirates, Ministry of Health, *United Arab Emirates Child Health Survey, 1987*.

ANNEX TABLE 4. PERCENTAGE DISTRIBUTION OF THE HANDICAPPED POPULATION (10 YEARS OLD AND OVER) IN THE SYRIAN ARAB REPUBLIC, BY SEX, EDUCATIONAL ATTAINMENT AND TYPE OF HANDICAP, 1981

**Table A. Percentage distribution of the handicapped male population (10 years old and over) in the Syrian Arab Republic, by educational attainment and type of handicap**

| Educational attainment | Blind | Deaf and mute | With one arm | Without arms | With one leg | Without legs | Paralysed | Mentally retarded | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Illiterate | 74.35 | 74.14 | 38.37 | 34.37 | 44.52 | 28.64 | 49.56 | 81.10 | 49.02 | 60.51 | 21.95 |
| Read and write | 14.03 | 16.09 | 31.44 | 29.01 | 30.05 | 29.95 | 24.74 | 10.71 | 27.79 | 20.96 | 31.52 |
| **Subtotal** | **88.38** | **90.22** | **69.80** | **63.38** | **74.57** | **58.59** | **74.31** | **91.80** | **76.82** | **81.48** | **53.47** |
| Primary | 6.44 | 6.63 | 18.10 | 18.03 | 14.79 | 25.37 | 16.52 | 4.88 | 14.83 | 11.56 | 26.35 |
| Intermediate | 2.33 | 1.62 | 6.10 | 5.92 | 4.79 | 7.20 | 5.38 | 1.64 | 4.17 | 3.58 | 9.32 |
| Secondary | 1.79 | 0.78 | 3.77 | 7.32 | 3.70 | 4.75 | 2.70 | 1.02 | 2.86 | 2.21 | 6.63 |
| Vocat./tech. diploma | 0.20 | 0.20 | 0.93 | 2.82 | 0.87 | 1.80 | 0.36 | 0.26 | 0.56 | 0.42 | 1.63 |
| Bachelor's or master's | 0.79 | 0.46 | 1.24 | 2.54 | 1.28 | 2.13 | 0.63 | 0.36 | 0.67 | 0.68 | 2.48 |
| Doctorate | 0.03 | -- | -- | -- | -- | -- | 0.05 | 0.01 | 0.03 | 0.03 | 0.09 |
| **Subtotal** | **11.59** | **9.70** | **30.14** | **36.62** | **25.43** | **41.24** | **25.65** | **8.17** | **23.13** | **18.48** | **46.50** |
| Not stated | 0.03 | 0.07 | 0.05 | -- | -- | 0.16 | 0.04 | 0.03 | 0.05 | 0.04 | 0.03 |
| **Total** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** |

ANNEX TABLE 4. *(continued)*

**Table B. Percentage distribution of the handicapped female population (10 years old and over) in the Syrian Arab Republic, by educational attainment and type of handicap**

| Educational attainment | Blind | Deaf and mute | With one arm | Without arms | With one leg | Without legs | Paralysed | Mentally retarded | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Illiterate | 87.60 | 85.60 | 65.45 | 62.08 | 71.93 | 53.60 | 74.63 | 90.62 | 75.39 | 80.50 | 54.53 |
| Read and write | 5.88 | 8.90 | 15.53 | 17.42 | 12.94 | 19.41 | 12.00 | 5.16 | 12.03 | 9.70 | 20.17 |
| **Subtotal** | **93.48** | **94.49** | **80.98** | **79.49** | **84.86** | **73.01** | **86.62** | **95.78** | **87.42** | **90.20** | **74.70** |
| Primary | 4.25 | 3.68 | 12.04 | 13.20 | 8.28 | 16.08 | 8.63 | 2.37 | 7.90 | 6.19 | 15.16 |
| Intermediate | 1.27 | 1.00 | 3.65 | 2.53 | 3.10 | 5.91 | 3.04 | 0.99 | 2.41 | 2.02 | 5.53 |
| Secondary | 0.76 | 0.67 | 2.22 | 2.81 | 2.07 | 2.96 | 1.28 | 0.47 | 1.47 | 1.09 | 2.88 |
| Vocat./tech. diploma | 0.08 | 0.06 | 0.48 | 0.84 | 0.91 | 0.92 | 0.18 | 0.21 | 0.31 | 0.22 | 1.09 |
| University and master's | 0.13 | 0.06 | 0.63 | 1.12 | 0.78 | 1.11 | 0.21 | 0.17 | 0.31 | 0.23 | 0.59 |
| Doctorate | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | 0.01 |
| **Subtotal** | **6.50** | **5.47** | **19.02** | **20.51** | **15.14** | **26.99** | **13.33** | **4.22** | **12.40** | **9.75** | **25.27** |
| Not stated | 0.02 | 0.04 | -- | -- | -- | -- | 0.04 | -- | 0.18 | 0.05 | 0.03 |
| **Total** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** |

ANNEX TABLE 4. *(continued)*

**Table C. Percentage distribution of the total handicapped population (10 years old and over) in the Syrian Arab Republic, by educational attainment and handicap**

| Educational attainment | Blind | Deaf and mute | With one arm | Without arms | With one leg | Without legs | Paralysed | Mentally retarded | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Illiterate | 79.96 | 79.01 | 45.03 | 48.24 | 51.67 | 40.36 | 58.95 | 84.44 | 57.82 | 67.95 | 37.88 |
| Read and write | 10.58 | 13.03 | 27.52 | 23.21 | 25.58 | 25.00 | 19.97 | 8.76 | 22.53 | 16.77 | 25.97 |
| **Subtotal** | **90.54** | **92.04** | **72.55** | **71.45** | **77.25** | **65.36** | **78.92** | **93.20** | **80.35** | **84.72** | **63.85** |
| Primary | 5.51 | 5.38 | 16.61 | 15.61 | 13.09 | 21.01 | 13.57 | 4.00 | 12.52 | 9.56 | 20.88 |
| Intermediate | 1.88 | 1.36 | 5.50 | 4.22 | 4.35 | 6.60 | 4.51 | 1.41 | 3.58 | 3.00 | 7.47 |
| Secondary | 1.35 | 0.73 | 3.39 | 5.06 | 3.27 | 3.91 | 2.17 | 0.83 | 2.40 | 1.79 | 4.80 |
| Vocational/ Tech. Diploma | 0.15 | 0.14 | 0.82 | 1.83 | 0.88 | 1.39 | 0.29 | 0.24 | 0.48 | 0.35 | 1.36 |
| University and master's | 0.51 | 0.29 | 1.09 | 1.83 | 1.15 | 1.65 | 0.47 | 0.29 | 0.55 | 0.51 | 1.56 |
| Doctorate | 0.02 | -- | -- | -- | -- | -- | 0.03 | 0.01 | 0.02 | 0.02 | 0.05 |
| **Subtotal** | **9.43** | **7.90** | **27.41** | **28.55** | **22.75** | **34.55** | **21.04** | **6.78** | **19.55** | **15.23** | **36.12** |
| Not stated | 0.03 | 0.06 | 0.04 | -- | -- | 0.09 | 0.04 | 0.02 | 0.10 | 0.05 | 0.03 |
| **Total** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), p. 147, developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

ANNEX TABLE 5. THE HANDICAPPED SYRIAN POPULATION (10 YEARS OLD AND OVER): FEMALES AS A PERCENTAGE OF MALES, BY EDUCATIONAL ATTAINMENT AND TYPE OF HANDICAP, 1981

| Educational attainment | Blind | Deaf and mute | With one arm | Without arms | With one leg | Without legs | Paralysed | Mentally retarded | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Illiterate | 118 | 115 | 171 | 181 | 162 | 187 | 151 | 112 | 154 | 132 | 248 |
| Read and write | 42 | 55 | 49 | 60 | 43 | 65 | 49 | 48 | 43 | 46 | 64 |
| **Subtotal** | **106** | **105** | **116** | **125** | **114** | **125** | **117** | **104** | **114** | **111** | **140** |
| Primary | 66 | 56 | 67 | 73 | 56 | 63 | 52 | 49 | 53 | 54 | 58 |
| Intermediate | 55 | 62 | 60 | 43 | 65 | 82 | 57 | 60 | 58 | 56 | 59 |
| Secondary | 42 | 86 | 59 | 38 | 56 | 62 | 47 | 46 | 51 | 49 | 43 |
| Vocational/ Tech. diploma | 40 | 30 | 52 | 30 | 105 | 51 | 50 | 81 | 55 | 52 | 67 |
| Bachelor's or master's | 16 | 13 | 51 | 44 | 61 | 52 | 33 | 47 | 46 | 34 | 24 |
| Doctorate | -- | .. | .. | .. | .. | .. | -- | -- | -- | -- | 11 |
| **Subtotal** | **56** | **56** | **63** | **56** | **60** | **65** | **52** | **52** | **54** | **53** | **54** |
| Not stated | 67 | 57 | -- | .. | .. | -- | 100 | -- | 360 | 125 | 100 |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

*Note*: ".." signifies that a figure is not available mathematically because of a 0% value for males in the original table.

ANNEX TABLE 6. PERCENTAGE DISTRIBUTION OF THE HANDICAPPED BAHRAINI POPULATION (10 YEARS OLD AND OVER) BY EDUCATIONAL ATTAINMENT, TYPE OF HANDICAP AND SEX, 1981

**Table A. Percentage distribution of the handicapped male Bahraini population (10 years old and over) by educational attainment and type of handicap**

| Educational attainment | Blind | Deaf and dumb | Deaf | Amputee | Paralysed | Mentally handicapped | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|
| Illiterate | 87.84 | 65.14 | 65.57 | 68.84 | 63.49 | 73.29 | 60.78 | 73.71 | 21.18 |
| Read and write | 7.36 | 17.43 | 22.95 | 18.09 | 20.63 | 13.35 | 21.57 | 14.78 | 28.58 |
| Primary | 2.23 | 11.01 | 7.38 | 4.52 | 9.13 | 6.53 | 8.33 | 5.81 | 19.45 |
| Intermediate | 0.68 | 4.59 | 1.64 | 4.02 | 3.57 | 3.56 | 2.94 | 2.55 | 12.49 |
| Secondary | 0.68 | 1.83 | 1.64 | 3.52 | 3.17 | 2.67 | 3.43 | 2.16 | 12.71 |
| Diploma | 0.51 | -- | 0.82 | 0.50 | -- | 0.59 | 1.47 | 0.55 | 3.09 |
| Bachelor's degree | 0.34 | -- | -- | 0.50 | -- | -- | 0.98 | 0.28 | 2.12 |
| Master's degree | 0.17 | -- | -- | -- | -- | -- | -- | 0.06 | 0.31 |
| Ph.D. or equivalent | -- | -- | -- | -- | -- | -- | -- | -- | 0.04 |
| Not stated | 0.17 | -- | -- | -- | -- | -- | 0.49 | 0.11 | 0.02 |
| **Total** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** |

ANNEX TABLE 6. *(continued)*

**Table B. Percentage distribution of handicapped female Bahraini population (10 years old and over) by educational attainment and type of handicap**

| Educational attainment | Blind | Deaf and dumb | Deaf | Amputee | Paralysed | Mentally handicapped | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|
| Illiterate | 93.52 | 84.13 | 91.55 | 85.71 | 81.50 | 88.17 | 78.49 | 88.24 | 41.44 |
| Read and write | 3.89 | 7.94 | 2.82 | 3.17 | 10.00 | 8.88 | 13.98 | 6.68 | 23.79 |
| Primary | 2.38 | 3.17 | 2.82 | 3.17 | 2.50 | 1.18 | 4.30 | 2.50 | 13.41 |
| Intermediate | 0.22 | 4.76 | 2.82 | 1.59 | 3.00 | 1.78 | 1.08 | 1.52 | 8.26 |
| Secondary | -- | -- | -- | 4.76 | 2.50 | -- | 2.15 | 0.89 | 9.44 |
| Diploma | -- | -- | -- | -- | 0.50 | -- | -- | 0.09 | 2.24 |
| Bachelor's degree | -- | -- | -- | 1.59 | -- | -- | -- | 0.09 | 1.31 |
| Master's degree | -- | -- | -- | -- | -- | -- | -- | -- | 0.07 |
| Ph.D. or equivalent | -- | -- | -- | -- | -- | -- | -- | -- | -- |
| Not stated | -- | -- | -- | -- | -- | -- | -- | -- | 0.04 |
| **Total** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** |

ANNEX TABLE 6. *(continued)*

**Table C. Percentage distribution of the total handicapped Bahraini population (10 years old and over) by educational attainment and type of handicap**

| Educational attainment | Blind | Deaf and dumb | Deaf | Amputee | Paralysed | Mentally handicapped | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|
| Illiterate | 90.35 | 72.09 | 75.13 | 72.90 | 71.46 | 78.26 | 66.33 | 79.28 | 31.26 |
| Read and write | 5.83 | 13.95 | 15.54 | 14.50 | 15.93 | 11.86 | 19.19 | 11.68 | 26.20 |
| Primary | 2.29 | 8.14 | 5.70 | 4.20 | 6.19 | 4.74 | 7.07 | 4.54 | 16.45 |
| Intermediate | 0.48 | 4.65 | 2.07 | 3.44 | 3.32 | 2.96 | 2.36 | 2.15 | 10.38 |
| Secondary | 0.38 | 1.16 | 1.04 | 3.82 | 2.88 | 1.78 | 3.03 | 1.67 | 11.08 |
| Diploma | 0.29 | -- | 0.52 | 0.38 | 0.22 | 0.40 | 1.01 | 0.38 | 2.67 |
| Bachelor's degree | 0.19 | -- | -- | 0.76 | -- | -- | 0.67 | 0.20 | 1.71 |
| Master's degree | 0.10 | -- | -- | -- | -- | -- | -- | 0.03 | 0.19 |
| Ph.D. or equivalent | -- | -- | -- | -- | -- | -- | -- | -- | 0.02 |
| Not stated | 0.10 | -- | -- | -- | -- | -- | 0.34 | 0.07 | 0.03 |
| **Total** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

ANNEX TABLE 7. THE EDUCATIONAL ATTAINMENT OF THE DISABLED BAHRAINI POPULATION* (FEMALES AS A PERCENTAGE OF MALES), 1981

| Educational attainment | Blind | Deaf and dumb | Deaf | Amputee | Paralysed | Mentally handicapped | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|
| Illiterate | 106 | 129 | 140 | 125 | 128 | 120 | 129 | 120 | 196 |
| Read and write | 53 | 46 | 12 | 18 | 48 | 67 | 65 | 45 | 83 |
| Primary | 107 | 29 | 38 | 70 | 27 | 18 | 16 | 43 | 69 |
| Intermediate | 32 | 104 | 172 | 40 | 84 | 50 | 52 | 60 | 66 |
| Secondary | -- | -- | -- | 141 | 79 | -- | 63 | 41 | 74 |
| Diploma | -- | .. | -- | -- | .. | -- | -- | 16 | 72 |
| Bachelor's degree | -- | .. | .. | 318 | .. | .. | -- | 32 | 62 |
| Master's degree | -- | .. | .. | .. | .. | .. | .. | -- | 23 |
| Ph.D. or equivalent | .. | .. | .. | .. | .. | .. | .. | .. | -- |
| Not stated | -- | .. | .. | .. | .. | .. | -- | -- | 200 |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

*Note*: ".." signifies that a figure is not available mathematically because of a 0% value for males in the original table.

* Bahraini national only.

ANNEX TABLE 8. PERCENTAGE DISTRIBUTION OF THE HANDICAPPED EGYPTIAN POPULATION (6 YEARS OLD AND OVER) BY EMPLOYMENT/ACTIVITY STATUS, TYPE OF HANDICAP AND SEX, 1976

**Table A. Percentage distribution of the handicapped male Egyptian population (6 years old and over) by employment/activity status and type of handicap**

| Employment/activity status | Blind | One-eyed | Deaf and mute | Deaf | Mute | Without arms | Without legs | Mentally disabled | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Self-employed | 8.82 | 22.13 | 10.91 | 16.21 | 11.30 | 19.53 | 16.42 | -- | 9.65 | 12.59 | 12.83 |
| Employer | 3.28 | 9.09 | 3.59 | 6.52 | 3.56 | 11.75 | 4.61 | -- | 2.90 | 4.90 | 5.48 |
| Paid employee | 10.81 | 49.27 | 46.02 | 47.17 | 39.31 | 45.00 | 37.97 | 0.21 | 55.60 | 36.07 | 39.20 |
| Unpaid family worker | 0.79 | 0.87 | 3.55 | 2.12 | 6.07 | 0.48 | 0.45 | 0.53 | 3.31 | 1.74 | 3.64 |
| Other unpaid worker | 0.01 | 0.03 | 0.02 | -- | 0.04 | -- | -- | -- | 0.02 | 0.02 | 0.02 |
| Unemployed | 1.05 | 0.39 | 1.07 | 0.48 | 1.05 | 0.53 | 1.34 | -- | 2.06 | 1.02 | 0.23 |
| Newly unemployed | 1.67 | 0.55 | 2.51 | 1.37 | 5.06 | 1.05 | 2.37 | 0.53 | 1.87 | 1.60 | 3.39 |
| Student | 27.58 | 8.71 | 14.58 | 8.30 | 13.52 | 4.19 | 7.29 | 1.97 | 7.99 | 12.97 | 28.24 |
| Housewife | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- |
| Retired | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | 0.83 |
| Unwilling to work | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | 2.52 |
| Aged (elderly) | 19.61 | 3.66 | 2.15 | 6.42 | 1.59 | 2.98 | 4.99 | 2.86 | 2.14 | 7.08 | 2.45 |
| Unable to work | 26.19 | 4.00 | 11.29 | 7.97 | 17.87 | 10.75 | 23.92 | 93.55 | 12.06 | 20.32 | 0.22 |
| Not stated | 0.19 | 1.29 | 4.32 | 3.44 | 0.63 | 3.72 | 0.63 | 0.34 | 2.40 | 1.71 | 0.95 |
| **Total** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** |

ANNEX TABLE 8. *(continued)*

**B. Percentage distribution of the handicapped female Egyptian population (6 years old and over) by employment/activity status and type of handicap**

| Employment/activity status | Blind | One-eyed | Deaf and mute | Deaf | Mute | Without arms | Without legs | Mentally disabled | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Self-employed | 0.21 | 2.08 | 0.60 | 1.07 | 0.59 | 2.91 | 3.42 | -- | 4.62 | 1.14 | 0.34 |
| Employer | 0.11 | 0.36 | 0.14 | 0.46 | 0.47 | 1.36 | -- | -- | 0.35 | 0.22 | 0.09 |
| Paid employee | 1.13 | 14.28 | 13.24 | 7.29 | 11.70 | 17.28 | 5.13 | 0.06 | 29.69 | 8.41 | 3.84 |
| Unpaid family worker | 0.10 | 0.10 | 0.11 | -- | 0.47 | 0.39 | 0.34 | 0.17 | 1.16 | 0.23 | 0.37 |
| Other unpaid worker | 0.02 | 0.02 | -- | -- | -- | -- | -- | -- | 0.04 | 0.01 | 0.01 |
| Unemployed | 0.06 | 0.17 | 0.92 | 0.08 | 0.24 | -- | -- | -- | 0.18 | 0.19 | 0.04 |
| Newly unemployed | 1.46 | 0.60 | 1.55 | 0.92 | 1.42 | 0.58 | 0.51 | 0.62 | 0.88 | 1.17 | 1.93 |
| Student | 23.62 | 12.31 | 22.31 | 26.69 | 13.71 | 25.24 | 10.77 | 2.71 | 12.57 | 18.93 | 17.50 |
| Housewife | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | 71.25 |
| Retired | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | 0.03 |
| Unwilling to work | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- |
| Aged (elderly) | 31.52 | 13.99 | 5.02 | 19.25 | 4.49 | 8.54 | 12.99 | 4.97 | 9.46 | 19.49 | 4.48 |
| Unable to work | 41.77 | 54.86 | 52.37 | 43.87 | 66.55 | 41.75 | 66.67 | 91.46 | 39.53 | 49.32 | 0.09 |
| Not stated | 0.02 | 1.22 | 3.73 | 0.38 | 0.35 | 1.94 | 0.17 | -- | 1.52 | 0.88 | 0.02 |
| **Total** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** |

ANNEX TABLE 8. *(continued)*

**Table C. Percentage distribution of the total handicapped Egyptian population (6 years old and over) by employment/activity status and type of handicap**

| Employment/activity status | Blind | One-eyed | Deaf and mute | Deaf | Mute | Without arms | Without legs | Mentally disabled | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Self-employed | 5.47 | 17.63 | 7.85 | 12.26 | 8.45 | 18.25 | 15.08 | -- | 8.90 | 9.68 | 6.70 |
| Employer | 2.05 | 7.14 | 1.58 | 4.96 | 2.73 | 10.96 | 4.14 | -- | 2.52 | 3.71 | 2.84 |
| Paid employee | 7.06 | 41.38 | 36.33 | 36.78 | 32.06 | 42.88 | 34.58 | 0.17 | 51.78 | 29.04 | 21.85 |
| Unpaid family worker | 0.52 | 0.69 | 2.52 | 1.57 | 4.58 | 0.48 | 0.44 | 0.45 | 2.99 | 1.35 | 2.04 |
| Other unpaid worker | 0.01 | 0.03 | 0.02 | -- | 0.03 | -- | -- | -- | 0.03 | 0.02 | 0.01 |
| Unemployed | 0.66 | 0.34 | 1.03 | 0.38 | 0.83 | 0.49 | 1.20 | -- | 1.78 | 0.81 | 0.13 |
| Newly unemployed | 1.60 | 0.56 | 2.21 | 1.25 | 4.12 | 1.01 | 2.17 | 0.56 | 1.72 | 1.49 | 2.67 |
| Student | 26.06 | 9.59 | 16.96 | 13.11 | 13.82 | 5.81 | 7.65 | 2.14 | 8.66 | 14.48 | 22.97 |
| Housewife | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | 34.95 |
| Retired | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | 0.44 |
| Unwilling to work | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- | 1.28 |
| Aged (elderly) | 24.21 | 5.98 | 3.04 | 9.74 | 2.36 | 3.41 | 5.82 | 3.36 | 3.22 | 10.23 | 3.45 |
| Unabled to work | 32.23 | 15.40 | 23.30 | 17.30 | 30.47 | 13.13 | 28.34 | 93.06 | 16.12 | 27.69 | 0.16 |
| Not stated | 0.12 | 1.27 | 4.16 | 2.66 | 0.55 | 3.59 | 0.58 | 0.26 | 2.27 | 1.50 | 0.50 |
| **Total** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** | **100.00** |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

ANNEX TABLE 9. THE EMPLOYMENT/ACTIVITY STATUS OF DISABLED PERSONS IN EGYPT (FEMALES AS PERCENTAGE OF MALES), 1976

| Employment/activity status | Blind | One-eyed | Deaf and mute | Deaf | Mute | Without arms | Without legs | Mentally disabled | Other | Handicapped population | Total population |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Self-employed | 2.38 | 9.40 | 5.50 | 6.60 | 5.22 | 14.90 | 20.83 | .. | 47.88 | 9.05 | 2.65 |
| Employer | 3.35 | 3.96 | 3.90 | 7.06 | 13.20 | 11.57 | -- | .. | 12.07 | 4.49 | 1.64 |
| Paid employee | 10.45 | 28.98 | 28.77 | 15.45 | 29.76 | 38.40 | 13.51 | 28.57 | 53.40 | 23.32 | 9.80 |
| Unpaid family worker | 12.66 | 11.49 | 3.10 | -- | 7.74 | 81.25 | 75.56 | 32.08 | 35.05 | 13.22 | 10.16 |
| Other unpaid worker | 200.00 | 66.67 | -- | .. | 1 175.00 | .. | .. | .. | 200.00 | 50.00 | 50.00 |
| Unemployed | 5.71 | 43.59 | 85.98 | 16.67 | 22.86 | -- | -- | .. | 8.74 | 18.63 | 17.39 |
| Newly unemployed | 87.43 | 109.09 | 61.75 | 67.15 | 28.06 | 55.24 | 21.52 | 116.98 | 47.06 | 73.13 | 56.93 |
| Student | 85.64 | 141.33 | 153.02 | 321.57 | 101.41 | 602.39 | 147.74 | 137.56 | 157.32 | 145.95 | 61.97 |
| Housewife | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. |
| Retired | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | 3.61 |
| Unwilling to work | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. | .. |
| Aged (elderly) | 160.73 | 382.24 | 233.49 | 299.84 | 282.39 | 286.58 | 260.32 | 173.78 | 442.06 | 275.28 | 182.86 |
| Unable to work | 159.49 | 1 371.50 | 463.86 | 550.44 | 372.41 | 388.37 | 278.72 | 97.77 | 327.78 | 242.72 | 40.91 |
| Not stated | 10.53 | 94.57 | 86.34 | 11.05 | 55.56 | 52.15 | 26.98 | -- | 63.33 | 51.46 | 2.11 |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

*Note*: ".." signifies that a figure is not available mathematically because of a 0% value for males in the original table.

ANNEX TABLE 10. PERCENTAGE DISTRIBUTION OF THE TOTAL HANDICAPPED EGYPTIAN POPULATION (15 YEARS OLD AND OVER) BY MAJOR OCCUPATIONAL GROUP, TYPE OF HANDICAP AND SEX, 1976

**Table A. Percentage distribution of the handicapped male Egyptian population (15 years old and over) by major occupational group and type of handicap**

| Major occupational group | Blind | One-eyed | Deaf and mute | Deaf | Mute | Without arms | Without legs | Mentally disabled | Other | Total population |
|---|---|---|---|---|---|---|---|---|---|---|
| Professional and technical | 17.43 | 5.99 | 7.48 | 4.43 | 2.83 | 9.37 | 4.06 | 6.86 | 0.11 | 8.42 |
| Administrative and managerial | -- | 0.67 | 1.45 | 1.01 | 0.58 | 4.85 | 0.43 | 0.99 | -- | 0.98 |
| Clerical and related | -- | 4.15 | 10.62 | 4.19 | 1.79 | 3.91 | 5.66 | 5.74 | 0.07 | 3.95 |
| Sales | 3.11 | 7.92 | 4.6 | 6.39 | 3.12 | 0.01 | 9.51 | 6.02 | -- | 5.52 |
| Services | 0.01 | 8 | 7.37 | 11 | 4.16 | 9.46 | 9.62 | 9.72 | 0.02 | 6.34 |
| Agriculture, fishing and related | 9.25 | 38.67 | 23.88 | 30.17 | 40.31 | 31.2 | 14.94 | 21.39 | 0.02 | 22.35 |
| Production and related and labour | 0.02 | 18.79 | 22.64 | 23.44 | 17.93 | 15.56 | 18.19 | 23.8 | 0.09 | 14.82 |
| Not stated | 1.69 | 2.05 | 4.48 | 2.66 | 5.84 | 3.03 | 4.49 | 7.46 | 0.14 | 3.56 |
| No occupation | 68.49 | 13.77 | 17.49 | 16.72 | 23.42 | 15.61 | 33.11 | 18.01 | 99.54 | 34.06 |
| **Total** | **100** | **100** | **100** | **100** | **100** | **100** | **100** | **100** | **100** | **100** |

**Table B. Percentage distribution of handicapped female Egyptian population (15 years old and over) by major occupational group and type of handicap**

| Major occupational group | Blind | One-eyed | Deaf and mute | Deaf | Mute | Without arms | Without legs | Mentally disabled | Other | Total population |
|---|---|---|---|---|---|---|---|---|---|---|
| Professional and technical | 1.38 | 4.5 | 2.68 | 2.46 | 5.34 | 8.62 | 1.05 | 7.71 | -- | 2.9 |
| Administrative and managerial | -- | 0.21 | 0.25 | 0.21 | 1.03 | 1.72 | -- | 0.66 | -- | 0.2 |
| Clerical and related | -- | 4 | 12.63 | 1.28 | 2.93 | 4.43 | 1.47 | 5.51 | -- | 2.87 |
| Sales | 0.2 | 1.96 | 0.29 | 1.18 | 0.34 | 3.2 | 2.1 | 2.29 | -- | 0.86 |
| Services | -- | 3.11 | 2.55 | 3 | 1.55 | 3.69 | 0.42 | 6.08 | -- | 1.68 |
| Agriculture, fishing and related | 0.17 | 2.41 | 1.63 | 1.82 | 2.41 | 5.17 | 0.42 | 2.6 | -- | 1.18 |
| Production and related and labour | -- | 1.88 | 2.72 | 2.03 | 3.97 | 2.22 | 4.19 | 5.73 | -- | 1.53 |
| Not stated | 0.18 | 1.33 | 1.42 | 0.96 | 1.55 | 0.49 | 0.42 | 12.12 | -- | 1.81 |
| No occupation | 98.07 | 80.59 | 75.83 | 87.04 | 80.86 | 70.44 | 89.94 | 57.29 | 100 | 86.96 |
| **Total** | **100** | **100** | **100** | **100** | **100** | **100** | **100** | **100** | **100** | **100** |

ANNEX TABLE 10. *(continued)*

**Table C. Percentage distribution of the total handicapped population (15 years old and over) by major occupational group and type of handicap**

| Major occupational group | Blind | One-eyed | Deaf and mute | Deaf | Mute | Without arms | Without legs | Mentally disabled | Other | Total population |
|---|---|---|---|---|---|---|---|---|---|---|
| Professional and technical | 11.03 | 5.67 | 6.17 | 4.01 | 3.56 | 9.35 | 3.79 | 0.09 | 7.11 | 3.3 |
| Administrative and managerial | -- | 0.59 | 1.12 | 0.83 | 0.73 | 4.66 | 0.38 | -- | 0.95 | 0.5 |
| Clerical and related | -- | 4.12 | 11.21 | 3.53 | 2.06 | 3.97 | 5.37 | 0.05 | 5.74 | 3.2 |
| Sales | 1.96 | 6.63 | 3.45 | 5.21 | 2.4 | 6.75 | 8.83 | -- | 5.55 | 2.87 |
| Services | 0.01 | 6.91 | 6.04 | 9.24 | 3.48 | 9.07 | 8.76 | 0.02 | 9.16 | 3.71 |
| Agriculture, fishing and related | 5.62 | 30.68 | 17.79 | 23.8 | 30.6 | 29.5 | 13.57 | 0.02 | 18.65 | 18.34 |
| Production and related and labour | 0.01 | 15.08 | 17.3 | 18.65 | 14.29 | 14.69 | 16.9 | 0.07 | 21.2 | 9.35 |
| Not stated | 1.09 | 1.9 | 3.68 | 2.28 | 4.72 | 2.87 | 4.1 | 0.11 | 8.12 | 2.56 |
| No occupation | 80.29 | 28.43 | 33.23 | 32.45 | 38.15 | 19.14 | 38.3 | 99.65 | 23.52 | 56.17 |
| **Total** | **100** | **100** | **100** | **100** | **100** | **100** | **100** | **100** | **100** | **100** |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

ANNEX TABLE 11. DISTRIBUTION OF MAJOR OCCUPATIONAL GROUPS OF DISABLED PERSONS IN EGYPT (FEMALES AS A PERCENTAGE OF MALES), 1976

| Major occupational group | Blind | One-eyed | Deaf and mute | Deaf | Mute | Without legs | Without arms | Mentally disabled | Other | Total population |
|---|---|---|---|---|---|---|---|---|---|---|
| Professional and technical | 8 | 75 | 36 | 56 | 189 | 92 | 26 | 112 | -- | 34 |
| Administrative and managerial | .. | 31 | 17 | 21 | 178 | 35 | -- | 67 | .. | 20 |
| Clerical and related | .. | 96 | 119 | 31 | 164 | 113 | 26 | 96 | -- | 73 |
| Sales | 6 | 25 | 6 | 18 | 11 | 46 | 22 | 38 | .. | 16 |
| Services | -- | 39 | 35 | 27 | 37 | 39 | 4 | 63 | -- | 26 |
| Agriculture, fishing and related | 2 | 6 | 7 | 6 | 6 | 17 | 3 | 12 | -- | 5 |
| Production and related and labour | -- | 10 | 12 | 9 | 22 | 14 | 23 | 24 | -- | 10 |
| Not stated | 11 | 65 | 32 | 36 | 27 | 16 | 9 | 162 | -- | 51 |
| No occupation | 143 | 585 | 434 | 521 | 345 | 451 | 272 | 318 | 100 | 255 |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

*Note*: ".." signifies that a figure is not available mathematically because of a 0% value for males in the original table.

ANNEX TABLE 12. PERCENTAGE DISTRIBUTION OF THE HANDICAPPED POPULATION (13 YEARS OLD AND OVER) IN JORDAN (EAST BANK), BY MARITAL STATUS, TYPE OF HANDICAP AND SEX 1983

**Table A. Percentage distribution of the handicapped male population (13 years old and over) in Jordan (East Bank), by marital status and type of handicap**

| Marital status | Visual | **Deaf and mute** | Physical | Mental | Multiple | Total |
|---|---|---|---|---|---|---|
| Single | 29.42 | 67.07 | 45.96 | 87.35 | 69.53 | 59.26 |
| Married | 63.11 | 30.67 | 50.20 | 9.93 | 25.15 | 36.69 |
| Divorced | 1.22 | 0.40 | 0.69 | 2.06 | 0.44 | 0.98 |
| Widowed | 6.25 | 1.87 | 3.16 | 0.66 | 4.88 | 3.07 |

**Table B. Percentage distribution of the handicapped female population (13 years old and over) in Jordan (East Bank), by marital status and type of handicap**

| Marital status | Visual | Deaf and mute | Physical | Mental | Multiple | Total |
|---|---|---|---|---|---|---|
| Single | 37.39 | 73.20 | 54.13 | 82.58 | 64.36 | 62.17 |
| Married | 25.00 | 14.93 | 21.30 | 6.82 | 9.94 | 16.31 |
| Divorced | 1.83 | 3.24 | 2.44 | 6.63 | 2.76 | 3.36 |
| Widowed | 35.78 | 8.63 | 22.12 | 3.98 | 22.93 | 18.17 |

**Table C. Percentage distribution of the handicapped male population (13 years old and over) in Jordan (East Bank), by marital status and type of handicap**

| Marital status | Visual | Deaf and mute | Physical | Mental | Multiple | Total |
|---|---|---|---|---|---|---|
| Single | 32.60 | 69.68 | 48.65 | 85.77 | 67.73 | 60.30 |
| Married | 47.89 | 23.97 | 40.66 | 8.90 | 19.85 | 29.37 |
| Divorced | 1.47 | 1.61 | 1.27 | 3.57 | 1.25 | 1.83 |
| Widowed | 18.04 | 4.75 | 9.42 | 1.76 | 11.18 | 8.49 |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

ANNEX TABLE 13. DISTRIBUTION OF THE HANDICAPPED POPULATION IN JORDAN (EAST BANK): FEMALES AS A PERCENTAGE OF MALES, BY MARITAL STATUS AND TYPE OF HANDICAP

| Marital status | Visual | Deaf and mute | Physical | Mental | Multiple | Total |
|---|---|---|---|---|---|---|
| Single | 127 | 109 | 118 | 95 | 93 | 105 |
| Married | 40 | 49 | 42 | 69 | 40 | 44 |
| Divorced | 150 | 810 | 354 | 322 | 627 | 343 |
| Widowed | 572 | 461 | 700 | 603 | 470 | 592 |

*Source*: ESCWA, "Social statistics and indicators in the ESCWA region" (E/ESCWA/SD/89/8), developed based on the United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability Statistics Data Base (1975-1986)* (New York, 1988).

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# WOMEN WITH DISABILITY IN EGYPT

*Heba Hagrass*

The problem of disability in all developed and developing countries is a crucial issue which must be addressed. Until now no country has been able to find a solution to this critical problem. The Global Meeting of Experts to Review the Implementation of the World Programme of Action concerning Disabled Persons at the Mid-Point of the United Nations Decade of Disabled Persons, which met in Stockholm in 1987, found that the World Programme of Action failed to place adequate stress on the needs of women with disabilities and that particular attention should be given to the improvement of their situation.

In most societies equality between men and women has not been achieved. This is particularly true in the Arab countries, where traditions reinforce the status quo. Furthermore, disabled people in these countries are almost ignored in the planning of the allocation of the scarce resources these countries have. Therefore, being a woman and disabled means being ignored and forgotten.

Since statistics about disabled women are scant and incomplete, these women are in a very disadvantaged situation. In developing countries, where the majority of disabled women live, a woman with a physical or mental disability faces multiple handicaps. All this leads to additional hardships for these women and even to tragedy.

It is generally assumed that disability affects men and women equally and that in developing countries there are more causes of disability for women than for men. However, in Egypt, statistics show that disability is more frequent in males than in females, with a ratio of 2 to 3, which may be due to the wars in this region.[1]

In all developing countries, women suffer from many causes of disability. This paper reviews briefly the causes of disabilities affecting Egyptian women. These causes fall into two categories. The first category is related to health problems: one of the main factors in health problems is malnutrition (Women and Disability, 1982). Owing to poverty in the developing countries, there are over 100 million persons disabled

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[1] For example, Egypt's Population and Housing Census in 1976 indicated an unusual sex ratio of handicapped males to handicapped females of almost 3 to 1. Quoted by ESCWA, "Social statistics and indicators in the ESCWA region (E/ESCWA/SD/89/8).

because of malnutrition. This amounts to one fifth of the total number of disabilities. Since traditions dictate that men should have priority in being fed because they are the main breadwinners, women are mostly fed with leftovers and sometimes they have very little food to survive on. Malnutrition is prevalent among pregnant Egyptian women and among small girls. The second cause affecting women in this category is vitamin A deficiency, which is responsible for a very high rate of blindness. Iron deficiency is also a main cause of the disabilities in women. Women with iron deficiency lack the vigour and vitality to carry out their daily duties: this deficiency leads to anaemia. Furthermore, their children are exposed to a higher risk of accidents in the home.

The next major category falls under traditions and beliefs. It is traditional in Egyptian society to marry off girls at an early age. Furthermore, many women do not use contraceptives either because of false perceptions about them or because they want to have as many children as they can to have help with their work. Therefore, high fertility rates are one of the major causes of disability among women. Very young mothers, as well as older mothers, suffer from maternal depletion and exhaustion which in the long run cause disability.

One of the very important causes of disability in general is endogamous marriage, which is traditional in Egyptian society. Figures show that 67 per cent of the parents of disabled persons are close blood relatives (El-Banna, 1989). Genetic factors account for 90 per cent of the cases of mental retardation. In 50 per cent of these cases the parents are cousins (Boylan, 1991).

The next crucial cause of disability in women and their children is illiteracy. In Africa 85 per cent of all women are illiterate. In Egyptian society male children have priority for education and then come female children, if it is financially possible. The education of women could mean a reduction in the frequency of disability, which is notably higher among illiterate women (Women and Disability, 1991).

Furthermore, it is traditional for women in rural areas to work from 12 to 16 hours a day, with the work divided between domestic chores, child care and work outside the home. All this leads to exhaustion and a greater liability to become disabled.

There are many problems that face women with disabilities, especially in developing countries. The first problem they face is social isolation. According to Boylan, disabled women are looked upon as objects of charity and pity (1991). Therefore these women lose their self-respect and develop feelings of inferiority which lead them to become morbid and unsociable. The loss of their self-respect makes these women withdraw from people and despise themselves, which is dangerous for them. Feeling inferior makes these women accept any treatment meted out to them, whether from their families, husbands or society, which is a reflection of their miserable

condition. Because these women fear social isolation, they are assigned to a much more inferior role in society and even in their own households. It is much more difficult for a woman with a disability than it is for a man with a disability to participate in public activities or social events, especially in rural areas. All the above leads these women to be socially isolated and to be sequestered behind closed doors.

In developing countries, where arranged marriages are still customary, disabled women are at a great disadvantage because the image of a woman is of a young, beautiful, active and physically perfect being. Such idealized images rob disabled women of their sexuality. Furthermore, because women in developing countries are often expected to perform hard physical labour, women with disabilities are not considered candidates for marriage and they are left to suffer from loneliness. Very few men will take the risk of marrying a disabled woman. Hence, there appears to be no future for the disabled women since marriage is seen as the ultimate goal for a woman in all Arab countries.

Child care is also the responsibility of women. This is a very difficult task for a disabled woman to undertake single-handed. However, there is no indication that children of disabled mothers have a higher accident rate than others. Furthermore, parenthood involves more than physical tasks: it involves providing security and love. A disabled mother has more time to read to her children and help them with their schoolwork. It has been found that children are capable of accepting the disability of a parent and can easily adjust to it.

Anxious parents who have cared for their handicapped child for so long are often fearful of the ideas and the overt signs of sexuality their children exhibit. They worry too much about any relation their disabled children may start to have with the opposite sex. They are not convinced that their disabled children can love, marry, have children and lead a normal life.

What is more surprising—and this I note from my own observation and experience—is that even professionals working with the disabled do not think that the disabled should be left to express their sexuality and further that they should be trained to suppress their feelings and sexual needs. They believe that a disabled person has enough problems to worry about and that there is no need to complicate her/his life with an unsuccessful love story.

The imposition of all these barriers and inhibitions and the encouragement of the repression of the sexuality of disabled persons has put them in a very difficult situation. Disabled persons are exposed to the dilemma of not only facing their own difficulties but also overcoming the prejudices and fears of their entourage. In reality disabled women are denied the right to love, the right to marry and the right to motherhood. Although disabled men can marry and enjoy family life, it is seen as shocking that a disabled woman should marry.

In Egypt, where social life is closed and where traditions and beliefs play an important role, the problem of disabled persons getting married is accentuated. It is necessary to look beyond the wheelchair to see the real person in it. There is no valid reasons why disabled as well as non-disabled persons cannot integrate, interact and even get married.

Since women with disabilities are unable to get married and since it is usually, in Arab countries, the husband who supports the family, these women may end up without anyone to support them. Therefore, education is seen as the first step to overcoming financial dependency for these women. In reality, in many Egyptian villages as well as other Arab countries, families do not send their able-bodied girls to school once they reach puberty. Since most of the disabled persons in Egypt live in rural areas and since there are feelings of shame attached to having a disabled child, especially a girl, disabled women have practically no access to education. While the illiteracy rate among disabled Egyptian men 10 years and over reaches 51.8 per cent, the illiteracy rate among disabled Egyptian women 10 years and over reaches 71.8 per cent.[2] This shows that the education opportunities for these women are minimal. Although disabled women badly need to be educated in order to support themselves, it has been documented that they are the least likely to have this opportunity.

Employment is very important for persons with disabilities. It offers them security and financial independence and gives them value and social status. Furthermore, it helps to promote integration and acceptance for all members of society. In Egypt, Law No. 39 of 1975 on rehabilitation states that all governmental and non-governmental organizations that employ more than 50 persons must have 5 per cent of their jobs reserved for the handicapped (Egyptian Ministry of Social Affairs, 1993). Statistics show that among Egyptian disabled males 15 years and over 65.9 per cent are employed: of these more than one third work in agriculture and related activities (33.9 per cent). Over one fifth are skilled and semi-skilled workers (22.5 per cent). However, the number of disabled women who are employed amount to only 13 per cent of the total number of disabled Egyptian women. More than one fifth are professionals and semi-professionals (22.3 per cent). An almost equal number are in clerical and secretarial work (22.0 per cent) (Nosseir, 1989). The above statistics show that the employment of disabled women is very limited.

In reality, even this small percentage of disabled women with jobs are mostly employed on paper and in company files only. They are not expected to go to work or to perform any task. Companies are only filling the 5 per cent mandatory quota by hiring disabled persons and giving them salaries without allowing them to go to work. By doing so companies avoid penalties and breaking the law, but they do break the

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[2] Egypt, Populatioin and Housing Census 1976, vol. I (Total Republic), Cairo, 1980, Ref. No. 93-15111.

people's pride and dignity. For all disabled persons, work gives them confidence and self-respect. Furthermore, it helps to build a healthy society where everyone can find her/his place to live.

Women with a disability at mid-life face the possibility of threefold discrimination based on sex, disability and age. It is known that women live longer than men. With age they are more liable to disabling disorders. Ageism in society discriminates against the elderly just as sexism discriminates against women (Boylan, 1991). With age women start to decrease their activity, which puts them in an even more inferior position. Furthermore, an ageing mother taking care of a handicapped child is faced with the worry about her ability to take care of the child and about what will happen to the child if she dies.

In Egypt, ageing disabled women are at a great disadvantage. If they are uneducated, untrained and unemployed, this means that they are dependent on their parents for support. The loss of her parents and being left alone with no help or financial support are real-life nightmares for the ageing disabled woman. Training and employment are the only solution to such a crisis.

There is another group of women not covered by the general definition of disabilities. These women are the mothers, sisters, wives or daughters of a disabled person. If we say that 10 per cent of the world population is disabled, this means about 500 million disabled persons. That means 500 million women around the world who in one way or another are involved in the care of one of their disabled family members. In many countries and societies, it is taken for granted that the care of a disabled person is the sole responsibility of women. The lives of these women (care-givers) are deeply altered with the disability of a member of their family. They may lose the opportunity for an education. They may have to sacrifice their jobs outside the home to take care of the disabled family member. They are also deprived of a lot of social and leisure activities because of the lack of time. These care-givers are helplessly locked in a vicious circle that they can never break. In Egypt, where outside help is not satisfactory, all the above problems apply to the Egyptian care-givers. This category of women also needs immediate assistance.

After having identified the complexity of the problems facing women with disabilities, we can start specifying the action needed and working out solutions. Whatever improves the status of women in general will improve the status of women with disabilities. The three goals of the United Nations Decade for Women—Equality, Development and Peace—are all equally important and inseparable in order to improve the condition of disabled women (Boylan, 1991). The other message of the Decade is that it is only when women themselves fight they can achieve their goals. Therefore, only women who have disabilities can identify and point out the major and most important obstacles that stand between them and complete integration into the social and economic life of their societies. As a physically disabled woman myself, I should

like to put forward a few solutions which I believe would help solve this complex problem.

The first step that should be taken is monitor closely the preventive measures to avoid impairment from the start. Children should be immunized against all disabling illnesses. Governments should tighten their control over handling and distribution of vaccines. Genetic counselling should be mandatory if endogamous marriage is unavoidable. It is estimated that 5 per cent of impairments could be prevented by simple genetic counselling. The next preventive measure that should be considered is to persuade young wives-to-be of the importance of birth control. They should understand that pregnancies at an early age and in older age may be the cause of impairments to them and their children.

The next step is early detection of any cause of impairment. There should be routine check-ups on babies and children to monitor their normal growth or to detect any problem in the initial stage. It has been found that most disabilities are sustained before the age of 5, and up to 53 per cent before the age of 10 (Stace, 1986).

The media constitute a crucial and effective tool to change people's attitudes towards impairment. People's ignorance and negativism build up social and psychological barriers that are more difficult for the disabled to break through than physical barriers. Negative attitudes become a cause of disability. Positive and constructive attitudes, however, help women with disabilities to integrate and interact in society. Moreover, the different images of women with disabilities in literature and television have a great influence on how these women are perceived and judged. Images of helpless, isolated and inferior beings build negative feelings toward the disabled. Disabled women leading satisfying lives and well integrated into society are rarely found in literature or movies. By failing to offer positive images, writers perpetuate negative stereotypes. Such images inspire awe and pity in the non-disabled. Awareness campaigns are necessary if attitudes concerning the disabled in general and disabled women in particular are to change. To achieve total social integration of the disabled, it is necessary to create unbiased attitudes which will develop into social and public acceptance.

It is very important for all disabled persons in general to be as independent as possible. The first step towards independence is education. It is important to stress the right of education and training for disabled women. New methods and technologies should be sought to be able to compensate for different kinds of disabilities. Physical barriers should be removed for easy access to schools, workshops and work.

The next step is the development of low-cost vocational rehabilitation models to adjust to the new employment realities. Disabled people should be provided with skills and/or income-generating activities that help to restore their productive value in

the eyes of the non-disabled and remove them from the category of helpless, dependent people who can only be a burden to others.

There is an urgent need to form disabled women's organizations. Such organizations are much needed in rural areas to help train and finance disabled women in their work. These women need awareness, organization, sisterhood and action. Therefore, local networks of the disabled in which women share experiences and knowledge are invaluable. Organizations at the Arab level and international level can exchange and make the best use of each country's experience. Organizations for parents of the disabled are also essential to facilitate contact among families for moral support and exchange of experience. Organizations must focus on the potential of the disabled and not on their handicaps. Disabled women must be assisted on site in their rural environment and provided with support and guidance. The building-up of day-care centres is a better alternative to boarding schools and nursing homes.

All the above are local-level solutions that each country could use as guidelines. Regional coordination is essential. A regional plan to update statistics on the disabled and to standardize the different categories of disabilities all over the region is needed. Statistics should include different categories covering sex, age and type of disability. This will facilitate the planning for each category and the allocation of resources according to real needs. The next step is the coordination between disabled women's organizations on the regional level in order to make the best use of their different experiences. The mass media in the region should publicize the problems of disability in the region to change social attitudes.

According to El-Banna, in Egypt, policies involving active programmes for the prevention of impairment, early detection and early intervention, community-based rehabilitation programmes, employment of the severely handicapped, physical adaptation (barrier-free design), the application of technology and normalization are still either in the planning or experimental stage (1989). However, I personally hope that we will soon pass this stage and move on to provide all disabled persons, and especially women, with all possible help to ensure a better future for everybody in our society. There is no single solution to the problems facing disabled women. Only combined and coordinated efforts can solve the major problems facing disabled women today.

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# THE ROLE OF GRASS-ROOTS NGOs, PARTICULARLY NGOs OF DISABLED WOMEN IN COMMUNITY-BASED REHABILITATION

*Abdallah El-Khatib*

## Introduction

In the mid-1960s, concern and interest in providing organized care for the disabled in Jordan began to be expressed, primarily through the voluntary sector and foreign charitable organizations. In 1967 the Swedish Organization for Individual Relief became the first organization in Jordan to begin working in the field of mental handicaps. It was followed in 1970 by the first Jordanian society in this field, the Mental Health Society. In 1972, the government sector became involved. It established a centre for vocational training for the disabled. With time, institutions specialized in care, education, training and rehabilitation of the disabled began to be established throughout Jordan by both the voluntary and government sectors.

The 1980s witnessed some quantitative and qualitative changes in care of the handicapped in Jordan. Quantitatively, there was an increase in the number of organizations and their beneficiaries as a result of the establishment of special education centres in the different governorates. Qualitatively, there was a focus on the type of programmes and the development of special education curricula. There was also an emphasis on outlining the role of the family and the community and increasing the interaction between them and the disabled. This was part of an attempt to reach the minimum level of integration of the disabled into the community and to change people's attitudes to a positive response.

Jordan's growing interest in the disabled came about as a result of the increased international concern. The General Assembly proclaimed the year 1981 International Year of Disabled Persons. This was followed by the United Nations Decade of Disabled Persons proclaimed by the General Assembly for the period 1983-1992. Through that decade, Jordan devoted considerable attention to the issue of the disabled, so much so that one can say that Jordan is one of the foremost developed countries in the region in the field of special education and handicapped care services. Table 1 below shows the number of centres in this field, their distribution, and how many people they served in 1993.

TABLE 1. NUMBER OF DISABLED CENTRES AND BENEFICIARIES IN THE VOLUNTARY, PRIVATE AND PUBLIC SECTORS, 1993

| | *Public* | *Private* | *Voluntary* | *Total* |
|---|---|---|---|---|
| *No. of centres* | 18 | 9 | 45 | 72 |
| *No. of beneficiaries* | 1 668 | 450 | 4 882 | 7 000 |
| *Percentage* | 24 | 6 | 70 | 100 |

The voluntary sector has the biggest responsibility for this field and renders most of the services to the disabled. It serves 4,882 handicapped people through 45 centres affiliated to 30 specialized charitable societies, providing 70 per cent of the services offered to the disabled in Jordan.

Table 2 below indicates the number of handicapped centres run by voluntary societies for the year 1993, the type of centres, and the number of people they serve.

Clearly, the field of mental disability has the largest number of centres, with 23 centres in the different governorates. These make up 51 per cent of the total number of centres for the disabled in Jordan. The 1,112 people who benefit from these mental disability centres make up 22.7 per cent of the total number of beneficiaries using the centres. Centres for deafness and hearing disabilities and cerebral palsy come in second, with seven centres for each, or 15.5 per cent of the total number of centres. The number of those benefiting from the cerebral palsy centres is 1,581, 32 per cent of the total number of beneficiaries. The hearing disability centres serve 1,480 people, or 30.3 per cent. Next in size come centres on visual disability, with 11.1 per cent of the total number of centres and 332 beneficiaries (6.8 per cent of the total), followed by the physically handicapped, with two centres (4.4 per cent of all centres available) serving 210 people (4.3 per cent of all beneficiaries). Centres for those with multiple handicaps come in last. With only two centres, they form 4.4 per cent of the total number of centres and serve 167 people, or 3.4 per cent of the total number of beneficiaries.

As for the distribution of services for the disabled in Jordan, the governorate of Amman offers services to the largest number of disabled people; it serves 2,833 persons, or 58.8 per cent of the total number of disabled people who are being served. The governorate of Zarqa is second, caring for 716 disabled people (14.6 per cent). Third comes Irbid, with 535 beneficiaries (11 per cent), then Balqa, serving 374 people (7.6 per cent), and Ma'an with 224 people (4.5 per cent), followed by Karak with 52 beneficiaries (3.1 per cent) and Mafraq, with 32 people (0.6 per cent) and finally Tafilah, offering its services to 16 disabled persons (0.3 per cent of the total number of disabled people cared for).

Most of these services are of an institutional nature. However, there are some community-based rehabilitation programmes which are carried out by a number of organizations. These programmes are carried out through professional mobile units. Both the local communities and organizations realize the vitality of the community-based rehabilitation programmes and how important it is to expand them. In Jordan, the core for community-based rehabilitation programmes are the programmes implemented by the voluntary sector centres. The programmes are directed towards the family and community and use meetings, lectures, and counselling.

### A. Focusing on women's issues

The year 1994 has been proclaimed the International Year of the Family, a year for all members of the family, male or female, able-bodied or disabled: hence the importance of focusing on women's programmes. The family is the basic central unit of any community, and the health, strength and productivity of each family member is reflected in the community as a whole. The more facilities available to help family members, the more each individual can participate in and contribute to his/her family and community, through a process of interaction and coexistence in which everyone can take part, regardless of sex, role, or physical or mental condition.

In developing countries, among which is Jordan, women have been responsible for the maintenance and stability of the family, owing to a number of biological, social, cultural and economic factors. The woman is the mother, the sister, the daughter, the worker, and sometimes, even the decision maker. The more qualified the woman is, the more she can contribute to the building of the community to which she belongs. Women make up half of any community and are the complementing part of man.

Yet despite the modern advances and progress taking place around the world, and the growing human rights movement, women in many communities, and especially in developing countries, still suffer from limitations which hinder their chances of participation in the building and development of their communities. This situation drew the attention of national and international organizations and led them to try and improve women's conditions as much as possible, through a series of recommendations and international charters and national laws addressing the issue of women. The first such attempt was the proclamation of the period 1976 to 1985 as the United Nations Decade for Women with the themes of Equality, Development and Peace. The Decade objectives were to draw up a strategy to help communities develop and to realize women's real and full participation in the economic, social, and political life of their communities. In the case of Jordan, perhaps the Jordanian Constitution and National Charter are good examples of the attention which the Kingdom has been placing on women's rights and the effective role they should play in public life.

TABLE 2. NUMBER OF VOLUNTARY SOCIETIES' CENTRES FOR THE CARE OF THE HANDICAPPED (C), TYPE AND NUMBER OF BENEFICIARIES (B) IN 1993

| | *Mental* | *Hearing* | *Visual* | *Physical Handicap* | *Cerebral palsy* | *Multi-handicap* | *Total* |
|---|---|---|---|---|---|---|---|
| Amman | | | | | | | |
| (C) | 7 | 1 | 4 | 1 | 2 | 1 | 16 |
| (B) | 564 | 1 100 | 326 | 160 | 666 | 17 | 2 833 |
| Irbid | | | | | | | |
| (C) | 6 | 1 | 1 | 1 | 1 | — | 10 |
| (B) | 223 | 6 | 6 | 50 | 250 | — | 535 |
| Zarqa | | | | | | | |
| (C) | 2 | 2 | — | — | 1 | 1 | 6 |
| (B) | 70 | 196 | — | — | 300 | 150 | 716 |
| Balqa | | | | | | | |
| (C) | 3 | 1 | — | — | 1 | — | 5 |
| (B) | 133 | 121 | — | — | 120 | — | 374 |
| Mafraq | | | | | | | |
| (C) | — | 1 | — | — | — | — | 1 |
| (B) | — | 32 | — | — | — | — | 32 |
| Karak | | | | | | | |
| (C) | 1 | — | — | — | 1 | — | 2 |
| (B) | 32 | — | — | — | 120 | — | 152 |
| Tafilah | | | | | | | |
| (C) | 1 | — | — | — | — | — | 1 |
| (B) | 16 | — | — | — | — | — | 16 |
| Ma'an | | | | | | | |
| (C) | 2 | 1 | — | — | 1 | — | 4 |
| (B) | 74 | 25 | — | — | 125 | — | 224 |
| **Total** | | | | | | | |
| (C) | 22 | 7 | 5 | 2 | 7 | 2 | 45 |
| (B) | 1 112 | 1 480 | 332 | 210 | 1 581 | 167 | 4 882 |

## B. Social concern for disabled women

If the situation of fully healthy and able-bodied women is difficult, then one can only try to imagine the situation of disabled women. Under what conditions do they live? What role do non-governmental organizations (NGOs) play in providing them with necessary services? What are the procedures followed to integrate them into society, through the society itself (for example, community-based rehabilitation)?

According to international estimates, there are about 400,000 disabled people in Jordan. With a 100:106 female to male ratio (according to the 1993 reports of the Department of Public Statistics), this means about 190,000 disabled women with various handicaps, in different age groups, and a broad geographic distribution. Only 2 per cent of these women are provided with services from the various groups working with the disabled, whether in rural or urban areas. These services are more limited in rural areas. The number of disabled women receiving services in the rural areas is 387 (48.59 per cent of the total number of beneficiaries of services available for the disabled in rural areas, and 7.91 per cent of the total number of beneficiaries in Jordan). It is worth noting that most of the services available in rural areas are educational programmes directed towards disabled women under the age of 16. As for vocational training programmes for the disabled, these—when found—are limited to the big centres concentrated in the larger cities. As for work opportunities, they are very rare owing to the general economic conditions in the Kingdom which include a high unemployment rate—about 30 per cent among fully healthy people.

In Jordan, the voluntary sector is the main sector that cares for disabled women, especially in areas that cannot be addressed by the public sector. In this sense, the voluntary sector complements the public sector. Since the beginning of handicapped care in Jordan in the late 1960s, voluntary societies have been receiving disabled men and women and providing them with necessary services. This developed into the establishment of certain societies specialized in caring for disabled women, such as the Islamic Association for the Care and Education of Blind Girls, the National Association for the Care of Blind Girls, the Regional Centre for the Rehabilitation and Training of Blind Girls, and other specialized centres. Other societies have established special divisions especially for disabled women, such as the National MultiHandicapped Society, the Al-Hussein Society for the Rehabilitation of the Physically Handicapped, the Young Moslem Women's Association (YMWA), the Swedish Organization for Individual Relief, the Mental Health Society, and other societies.

Most of these societies focused on achieving educational and rehabilitation goals, at the expense of social goals and the integration of the disabled into society. But as public awareness grew with regard to the disabled, their rights and their abilities, many of the programmes became more comprehensive in the services they offered. No longer were they confined to academic programmes; they went beyond

classroom instruction and expanded into vocational training programmes, rehabilitation and employment. All this was done through organized activities offered by local community voluntary societies. Examples of such programmes for disabled persons include courses offered at vocational training centres affiliated with sheltered workshops at the YMWA. The employment programmes of the Al-Hussein Society for the Rehabilitation of the Physically Handicapped and the Friendship Association for the Blind are also good indicators of communities' social awareness with regard to the importance of utilizing disabled women's abilities in productive work and the necessity of achieving their rights.

With time, progress has been made and this has made it possible for disabled women to perform productive work under normal conditions and in everyday life. Lately, this progress has been evident in the fact that many partially disabled women, including the blind, are working in public organizations and ministries, and even in the private sector.

Since the beginning of the 1980s, international organizations, such as the United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA), have been concentrating on the issue of community-based rehabilitation in the refugee camps. The beginning of the 1990s saw an increased awareness of the importance of integrating disabled men and women into the community through the adoption of a method of "rehabilitation based on the community" in order to blend disabled women into their community, through their community.

Community-based rehabilitation is founded on the premise that disabled men and women have a right to live a normal life, just like normal, healthy people. As part of a big family (the community), they have the right to an education, training, rehabilitation services, employment, and all other rights to which every person is entitled according to divine and earthly laws. The community has a duty to give disabled persons the chance to take part in community-building and development, each according to his/her ability and capacity. The main idea behind community-based rehabilitation programmes is that the community has an obligation to address the issues and needs of its people. The community has a duty to utilize the capabilities and resources available within it to meet these needs, in cooperation with specialized parties.

The full participation of the local community is essential for the success of any development project. Moreover, it is an effective method of changing people's attitudes, especially in rural areas where the problem of disability affects not only the disabled persons themselves, but also their families and community as a whole. In rural communities, the problem of disability is accompanied by other difficulties, such as a lack of good-quality, essential, basic services, such as health care and education, and a shortage of resources and facilities and qualified manpower available to care for the disabled. In addition, the continuous increase in population has resulted in an increase

in the number of disabled people. All this poses a challenge with regard to the procedures being implemented to improve services and address the problems of the increasing numbers of the disabled.

Studies show that disability in general is not so much a problem of limited mental or physical abilities, as much as it is a problem of the reaction to the presence of a disabled person by those around him/her. Therefore, disability is basically a result of the attitude of the community towards the disabled. This attitude of course has its effect on disabled individuals since, naturally, they react to and are affected by their environment.

Given the abilities that can be developed through effective rehabilitation, the word "disability" does not have to mean "impotence". Community-based rehabilitation programmes aim at redefining the meaning of this word. They seek to qualify the disabled to the same extent as the rest of the community. The aim is not to qualify disabled persons outside their habitat, but to integrate them into their local community so that there can be genuine participation and interaction in the larger sense of the word.

The broader philosophy behind community-based rehabilitation is making the integration of disabled persons into the community a priority. It is important to concentrate on integration more than on coming up with new and highly specialized institutional services because such services lead to isolation of the disabled and are far from the fundamental interaction which they need with the community in which they live.

### C. THE PHILOSOPHY OF COMMUNITY-BASED REHABILITATION

The idea of community-based rehabilitation arose as a result of the problems faced by institutional rehabilitation. By nature, closed institutional rehabilitation was unable to serve the purpose for which it was established. It did not have the capacity to absorb the number of people who needed its services. Moreover, it was designed in a manner that encouraged isolation and seclusion because of the nature of its programmes, which do not facilitate interaction between the disabled and the surrounding environment. In addition to all this, there is a lack of necessary financial resources, a scarcity of qualified and specialized manpower, and a limited number of centres established for institutional rehabilitation.

The above factor made it imperative to try and find an effective and efficient alternative, one based on participation, equality, interaction, and integration of the disabled into the community. The alternative must work within the capabilities and capacity of the local community for the rehabilitation of the disabled, especially in rural areas and in the case of deprived minorities, such as disabled women. The result

would most likely be effective integration, which remains the purpose of all rehabilitation programmes.

### D. Approaches of community-based rehabilitation

Community-based rehabilitation has two main approaches:

**The first approach**: This approach places the biggest part of the responsibility on the family and the local community. It aims at simplifying all procedures to an extent that allows the family and community to interact with the care and rehabilitation needs of the disabled. They do this within the local capabilities and resources, in cooperation with all members of the community, adapting the local conditions to achieve this aim, with the help of existing voluntary efforts, and without resorting to specialized centres.

**The second approach**: This approach is founded on expanding the base of rehabilitation services by replacing highly specialized institutional services with community centres closely connected to central institutions specialized in therapeutical procedures. Such a measure is aimed at integration of the community centres with the specialized institutions. The institutions would serve as a pivot for expertise, development and specialized therapy and would improve current therapy methods in the community centres for the disabled.

### E. The role of grass-roots NGOs in integrating disabled women into society

It has previously been noted that the aim of any rehabilitation programme is to "integrate" the disabled into their community in the wider sense of the word, so that they may adapt and fit into the community as constructive members.

NGOs play a significant role, indirectly, in this integration process, if "integration" is defined as providing the disabled with all their needs through the community in which they live. Voluntary societies specialized in care for disabled women provide physical rehabilitation, as well as academic and vocational training and employment. Other societies working in the area of family care, such as the Jordanian Association for Family Planning and Protection, play an important role in public awareness and health education programmes for mothers, stressing the importance of birth spacing, family planning, and the ideal reproductive age for women, and showing the clear connection between these factors and the preventive role they play with regard to conceiving disabled children. Another example is the Women's Organization for Struggle Against Illiteracy, whose long-term goal is to eliminate ignorance among women through raising the educational level of illiterate women. Women's education helps prevent the birth of abnormal children; it also helps to strengthen women in general. There are also around 300 voluntary societies in Jordan which have established

and support kindergartens that care for about 30,000 children. These societies contribute to caring for children and providing a healthy and safe environment for them to grow up in. They look after the children in such a way as to prevent them from suffering any accidents which could lead to a disability.

Even women's societies working in the field of economic development have given considerable attention to caring for disabled women. The Jerash Women's Society is a leader in employing disabled women.

As for the societies specialized in caring for disabled women, many of these societies provide medical diagnosis, therapy, care and rehabilitation. Through these medical services the societies help disabled women develop their abilities in a manner that gives them a chance to interact with the rest of the community to a great extent. The methods used by these societies include therapies and provision of physical impairment aid devices, such as those for hearing disabilities, and rehabilitation services for the blind, whether they be therapeutical services or medical aid devices. There are also services, especially rehabilitation services, offered to the physically handicapped and those with cerebral palsy. In this respect, the General Union of Voluntary Societies in Jordan (GUVS) helps by providing medical rehabilitation and providing the necessary medical equipment, whether for hearing, visual, or physical disabilities. GUVS does so through the rehabilitation programmes carried out through its annual plans and activities.

As for special education, that is the one service which all societies specialized in care for the disabled provide, either fully or partially. It should be noted that women receive 40 per cent of the services which the voluntary sector provides for the disabled, through institutional programmes or semi-integral programmes.

Among such academic programmes are the two offered by the Islamic Association for the Care and Education of Blind Girls. One of these programmes is completely institutional, providing education for blind women by blind teachers. The other is somewhat of a community integration programme in which blind girls enrol in government schools for sighted children and start the preparatory stage of school. There, they are taught under normal conditions and in a natural community environment. It is worth mentioning that many blind women have finished their high school education and are now attending university. The number of beneficiaries of the first programme so far is 20 women; they are taught by three blind women and four sighted women, and the headmaster of the school is blind. There is a clear sense of cooperation between the school and the local community. As for the second programme, 15 girls have benefited from it so far.

As for hearing disabilities, the academic services offered there are clearly institutional. However, a trend has recently started to teach speech with what is left of the hearing faculty and to use the aid of medical devices to improve hearing as much

as possible. This new approach is fast growing. GUVS has adopted an experimental programme, in cooperation with the Holy Land Institute for the Deaf, to achieve this aim by developing speech in schoolgirls with hearing disabilities through the use of medical hearing aids.

With regard to mental handicaps, the special education programmes provided to this group are simple and are directed towards those with mild and moderate mental handicaps, as well as slow learners. These programmes concentrate on the relation between academic skills and everyday life activities, and they are completely institutional. In relation to vocational integration, which is done through occupational and vocational training and rehabilitation, there is a limited number of voluntary centres tackling this issue, basically through two types of programmes. The first programme is completely institutional and is for mild mental disabilities. Examples of this type of programme are the vocational training project of the Young Moslem Women's Association, the Mental Health Society and the Swedish Organization for Individual Relief. The second programme is semi-institutional for visual, physical, and hearing disabilities. It involves vocational training in the centres of the societies, in cooperation with healthy women from outside the centres. Examples of this programme are the Al-Hussein Society for Rehabilitation of the Physically Handicapped, the Al-Sindyanah Society for the Blind, and the centres for the deaf and dumb.

As for integration in the field of work, this is considered to be a very advanced stage of the integration process. It is much closer to community integration because the disabled women will have already finished the previous levels of training and be ready to work. Integration here aims at helping disabled women achieve economic independence through working under normal work conditions. This, of course, is a big responsibility and poses a tremendous challenge to the disabled woman to prove herself and her ability to perform the job assigned to her. It also creates a consensus throughout the community to give disabled women jobs that are suitable to their abilities, because such jobs give the women a chance to succeed at their work and provide them with an incentive to continue. Job integration also encourages attempts to provide the financial and environmental facilities that make it easier for disabled women to do their work in an optimal way.

However, this kind of integration programme (work integration) is rather limited. As noted above, voluntary societies concentrate on training and qualifying disabled women on medical, academic and vocational levels, all of which pave the way for employment in the future. Work integration remains a relatively indirect aim for voluntary societies. However, the Disabled Employment Programme which GUVS has adopted is considered a clear indicator of the voluntary sector's concern for all types of work integration. There are now five disabled women benefiting from this programme, through managing their own sales booths.

As for the rights of the disabled, there has been a rapidly growing interest for them in Jordan, and many laws have been enacted concerning their right to a job if their qualifications match the job requirements, especially in public jobs. One can now see many phone operators, teachers and nurses who are partially disabled, and who do their job with great precision.

As noted, job integration is related to the community's awareness of the importance of this work and how beneficial it is to disabled women, their families, and the whole community, psychologically, economically, and socially. Since the core of job integration is creating interaction and relationships between disabled women and their community, this implies that the women must have attained sufficient skills to begin work and gain economic independence, thus achieving economic integration.

The question remains as to how to achieve social integration, which is the other side and the complement of economic integration. In this aspect, some voluntary societies organize programmes on the relation between the families and the community on one side, and the disabled on the other. These programmes concentrate on social issues, such as marriage of disabled women, or their ability to carry out the work in leading administrative positions.

As for the cost of integrating disabled women into society, taking into account that all services offered by the voluntary societies in the field of handicapped care contribute to this integration process, the running cost of the whole programme in the voluntary sector is about 3 million Jordanian dinars (JD) annually. GUVS contributes largely to this amount, whether through building centres for these services or by starting and managing annual programmes, especially training and qualifying programmes for those working with the disabled, who number about 578 persons.

## F. Facilities available for disabled women in Jordan

Care for the disabled is relatively new in Jordan, and little attention is given to community-based rehabilitation, especially in the case of disabled women. Nevertheless, much has been accomplished in the area of working with the disabled and the services and facilities offered them. There are three main types of facilities, as outlined below.

### First: legal facilities

These are based on Islamic values, the Jordanian Constitution, the National Charter, the education laws, the Universal Declaration of Human Rights, the United Nations Declaration on the Rights of Disabled Persons, and the Welfare of the Disabled Law. They emphasize the rights of disabled men and women alike, without any discrimination. The most recent legislation on this issue is the Care for the

Disabled Law No. 12 of 1993, which stressed the rights of the disabled and outlined the responsibilities of the various concerned parties in implementing this statute.

Item (A) of article VIII of the above mentioned law clearly stresses the right of the disabled to be fully integrated into public life, as a main aim and goal which the disabled must be helped to achieve through the following:

(a) The right of the disabled to education, including higher education, each according to his/her ability;

(b) The right of the disabled to employment appropriate to their abilities and qualifications;

(c) The right of the disabled to practise sports and to recreation;

(d) The right of the disabled to health care and physiotherapy;

(e) The right of the disabled to a suitable environment which provides them the freedom of safe mobility and transportation;

(f) The right of the disabled to obtain devices and equipment which help them move and live independently;

(g) The right of those with severe and multiple handicaps to education, training and rehabilitation;

(h) The right of the families of the disabled to aid and supporting services;

(i) The right of the disabled to decision-making in matters that concern them.

The above-mentioned items are not theoretical. The National Council for the Welfare of the Disabled has begun laying out the procedures that will ensure the implementation of these items, stressing to the concerned parties the importance of implementation of the responsibilities handed to them in accordance with this law. The most notable step taken by the Council was the establishment of an employment office for the disabled, which commenced its work about six months ago. Since then the office has found jobs for 287 disabled persons, about 25 per cent of whom were women.

It was stated in paragraph two, item (A) of article IV of the Care for the Disabled Law No. 12 of 1993 that all government and private sector companies which employ between 25 and 50 people must employ at least one disabled person.

Companies with over 50 employees must allocate no less than 2 per cent of their posts for the disabled.

Other legal facilities for the disabled in Jordan include exemptions. Item (A) of article V of the above-mentioned 1993 law indicates that all educational and medical materials, aids for the handicapped, devices, equipment and spare parts, transportation for schools, programmes and centres for the handicapped, as well as individual and joint productive projects owned and operated by the disabled, and cars especially designed for the use of the handicapped; all these are exempted from import taxes and duties and any other taxes or fees. The law also refers to the possibility of obtaining a driver's licence for physically handicapped or deaf and dumb people.

Legal actions, such as the full exemption from taxes and fees for any material or machine or tool which disabled women might need to manage their life, help these women achieve independence and integration into public life.

**Second: environmental facilities**

These facilities are the adjustments made to the physical environment of the disabled to facilitate their integration into society. There are three sides to this:

(a) Adapting the physical environment of the teaching, training and rehabilitation centres where the disabled obtain these services. This mainly includes adapting the buildings to allow easier access, and providing adapted teaching aids for teaching, training and rehabilitation purposes;

(b) Adapting the physical environment of workplaces;

(c) Adapting the general environment of the community, which includes providing special recreational services for disabled women. Voluntary societies have been successful in this field. They provide suitable amusement and sports activities for young disabled girls. As for adult disabled women, the Jordanian Sports Federation for the Handicapped provides them with exercise facilities. This area also includes adaptation of public buildings and organizations to facilitate movement for the disabled;

**Third: social facilities**

These are the support services which provide the base to implement the other facilities. They involve community attitudes and the services it offers the disabled. In general, social facilities include:

(a) Communication and information facilities: The most notable of these facilities is the news in sign language for the deaf and dumb, which is broadcast on

Jordan Television, and the radio and television programmes, conferences and seminars which identify the number of disabled people, especially disabled women, and their right to obtain appropriate services.

(b) Attitudes towards disabled women: These include the community's acceptance of disabled women as people with full rights, despite their handicaps, and acknowledgement of the importance of their presence in the community. There have been many charity walks supporting this issue, and many private companies have employed disabled women as a sign of their positive support of this group and in an honest attempt to provide services that help integrate disabled women into their community.

## G. Obstacles to integration of disabled women into Jordanian society

Despite the accomplishments made in integrating disabled women into Jordanian society, there are many obstacles and limitations which define the level and degree of integration. Among these problems are:

(a) Social obstacles: These include old-fashioned traditions and values and ill-founded concepts which prevail in the society in general and especially in rural areas. These do not give equal opportunities to able-bodied women to learn, train and qualify themselves in the same way as men. The same goes for the disabled: disabled women come in second place, after disabled men, which delays, and sometimes even eliminates, their chance to obtain services. This, coupled with the strict old- fashioned prohibition against women in general—let alone disabled women—going out into society, greatly impedes integration of disabled women into the society.

(b) Psychological obstacles due to the disabled women themselves: Disabled women in general have accepted being treated as second-class citizens in the world of the disabled, and as fourth-class citizens in the community as a whole. The main reason for this attitude among disabled women could be that they themselves do not realize their capabilities as a result of the wrong way in which they are brought up. They develop a sense of failure and do not realize the importance of receiving the available services, and thus, their demand to receive these services decreases.

(c) Social and family obstacles: These are characterized by the family's economic status. Many families are unable to pay even the symbolic fees required by the centres for the handicapped, and there are not enough free services. Families also need to realize how important it is for their disabled daughters to receive these services, and to arrange their priorities accordingly. The society's negative attitude towards the disabled also poses a problem; many communities do not believe in disabled people's capabilities and are insensitive to their needs and rights.

(d) General economic obstacles: There are not enough specialized centres for the disabled, especially in rural areas. When found, these centres provide limited services, both in quantity and quality, owing to the limited resources available to those working with the disabled. The increase in demand for these resources is continuing, in the light of the general economic situation.

(e) Environmental obstacles: The environment and habitat in which disabled women live are not fashioned in a way that allows them to move freely and safely and to enter all facilities and services available in the community.

(f) Legal obstacles: Despite the improvements in legislation concerning the disabled, and the enactment of a law especially for them, there are many areas that have not been covered clearly in the law: for example, the enforcement of handicap-prevention measures, such as premarital testing of prospective spouses. Furthermore, some of the provisions of the law are difficult to implement, in the light of the limited economic capabilities and the priorities of development in Jordan. The available services are not sufficient to satisfy the increasing needs of the growing numbers of the disabled.

(g) Informational obstacles: Until not very long ago, the image of disabled women portrayed in the mass media was very negative and marginal and there was a limited number of programmes that dealt with this issue. This led to greater isolation of disabled women from society.

(h) Planning and coordinating obstacles: There is a lack of planning and coordination between the different parties working with and for the disabled in Jordan. In some parts of the Kingdom, there are a number of organizations working, while in others there are none. There is also a lack of cooperation and coordination between these bodies in the programmes offered to disabled women, as few in number as these programmes are.

## H. DEVELOPMENT STEPS TO BE CONSIDERED

Both the ethics of religion and the Constitution of Jordan have stressed the importance of preserving the human rights and dignity of all Jordanians, men and women alike. However, there is still much that needs to be done for the disabled in order to improve the conditions surrounding them and to facilitate their broader integration into society.

Any future plan for improving the conditions of disabled women must be formulated on the premise that a disabled woman is a citizen with full rights and is a part of the society: the best way to satisfy her needs is through this society to which she belongs, and under normal conditions as much as possible. It is best to try to stay as far away as possible from isolated services and centres while attempting to integrate

disabled women into the society. If this is to be done, then all the different parties will have to work together and cooperate in carrying out their different programmes. The following suggestions might be of help:

(a) Any development plan must be based on actual, precise and accurate field data. Currently, the information available on the conditions of disabled women in Jordan is limited and dispersed; it is not collected in one place which can be considered an accessible source of information. This may be due to the lack of coordination among the parties involved when it comes to exchange of new information, in addition to the sensitivity of the issue of disabled women. It is therefore important to increase the number of research and studies relating to disabled women and to collect such studies and information all in one place to facilitate their accessibility.

(b) Public awareness campaigns should be organized to focus on the positive features of disabled women and could help change and improve people's attitudes towards them. It is also important to make disabled women and their families aware of the services available to them and how they can obtain them.

(c) Disabled women in Jordan must take part in all levels of planning that formulate policies concerning them, and they must have representatives in the various committees and councils.

(d) Appropriate health care and nutrition are vital as a right for disabled women in particular, and for women in general. Good health care and nutrition play a role in preventing the handicaps that might result from improper health habits or malnutrition, especially in rural areas.

(e) Families must be encouraged to reconsider the roles and duties traditionally assigned in the home, especially those assigned to disabled women. This will contribute to giving these women new responsibilities, which will affect their integration into the society. It might be helpful to establish general family counselling services and special services for families of disabled women.

(f) Voluntary societies and grass-roots NGOs should be provided with sufficient financial support to enable them to play a bigger part in the integration of disabled women into society, because the structure and characteristics of these organizations make them ideal for the job. The whole philosophy behind community-based rehabilitation depends on the participation of the local community in a voluntary manner, and the adoption and implementation of this philosophy by voluntary societies. These societies, which are in every local community in Jordan, are the most capable of reaching every disabled woman and offering her the services she needs.

(g) Finally, more should be done to help disabled women start their own small projects, particularly in rural areas, in order to help them attain economic independence, which will make social integration easier. Such projects would also allow disabled women to contribute productively to the national economy.

In conclusion, one must admit that Jordanian NGOs are still at the beginning of a very long road leading towards their goal and to giving disabled women a hand in helping them to learn to take care of themselves, within a country-wide community-based rehabilitation programme.

# دور الجمعيات التطوعية الشعبيـــة في دمج المرأة المعوقة في المجتمع

## وضـــع الأردن

### ملخـــص


لا شك في أن موضوع العوق والمرأة، من المواضيع التي أثارت الجدل عبر السنوات الأخيرة وحظيت بالإهتمام على كافة المستويات الدولية والإقليمية والوطنية وحتى على مستوى الأسرة والفرد. وذلك لكونه من الظواهر الاجتماعية والاقتصادية متعددة التركيبات والإنعكاسات، ونظرا للتأثير المباشر للعوق على الفرد في الأسرة والمجتمع من النواحي الاقتصادية والاجتماعية والنواحي الأخرى للحياة. وتصبح مواجهة ظاهرة العوق أكثر صعوبة إذا ما قامت على عاتق قطاع أو فئة من المجتمع دون أخرى. وبالتالي فإن الطريقة الأنجع في التعامل مع العوق في مجتمع ما هي في تضافر جميع القطاعات في ذلك المجتمع، وتنظيم وتنسيق الجهود لتقديم الخدمات المطلوبة الى المعوقين والوصول بهم جميعا الى مستوى التكيُّف والإندماج في المجتمع، بكل ما لهذه الكلمة من معنى.

ويُعتبر القطاع التطوعي من أكثر القطاعات تحسُّساً لمشاكل وهموم أفراد المجتمع. وهو يمثِّل الرديف الفعَّال والمبادر للقطاعات الأخرى في تلبية احتياجات الفئات المحرومة والأقل حظاً، ومنها المعوقون ذو الاحتياجات الخاصة.

وفي الأردن، احتلت قضية العوق جزءاً كبيرا من برامج القطاع التطوعي الذي بادر متعدياً للمساهمة في تحسين أوضاع المعوقين وتسخير إمكاناته المتاحة لدمجهم في المجتمع.

والأصل أن لا يجري الحديث عن موضوع العوق بالفصل بين الجنسين، ولكن تم التركيز على الجنس هنا نظرا الى الوضع الخاص الذي تعيشه المرأة المعوقة. ويُلاحظ أن القطاع التطوعي، منذ بداية اهتمامه بالفئات الخاصة، قد أولى اهتماماً واضحا للمرأة المعوقة. وعمل على توفير الخدمات والبرامج اللازمة لها، سواءً البرامج الأكاديمية أو المهنية أو التأهيلية أو التشغيلية، لمساعدتها على تحقيق أقصى درجة من الاستفادة من قدراتها وتحقيق الاستقلال الوظيفي والإندماج في المجتمع، بواسطة المجتمع نفسه أو ما يسمى بالتأهيل المجتمعي. والفكرة الرئيسية في برامج التأهيل المجتمعي هي تحديد مسؤولية المجتمع المحلي تجاه قضاياه واحتياجاته وتوظيف أمكاناته وموارده المحلية المتاحة لتلبية هذه الاحتياجات. والهدف النهائي لهذه البرامج هو دمج المرأة المعوقة في مجتمعها باعتبار ذلك أولوية تفوق استحداث التدابير الخاصة والخدمات المؤسسية عالية التخصص التي تميل الى العزلة والتي لا يمكن أن تلبي كافة الاحتياجات وذلك لمحدودية الموارد المالية والفنية، بالاضافة الى القضايا النفسية والاجتماعية والحضارية المتصلة بها. وإذا أُعتبرت معظم خدمات المراكز التطوعية البالغ عددها ٤٥ مركزا تابعا الى ٣٠ جمعية تقدم خدماتها الى حوالي ٥٠٠٠ معوق ومعوقة، خدمات مؤسسية الصبغة فلا بد من التركيز على برامجها ذات الاتجاه المجتمعي في تأهيل المعوقات بدءا

من برامج التأهيل الطبي التشخيصية والعلاجية التأهيلية، ومرورا بالتأهيل الأكاديمي والمهني، وانتهاء ببرامج الدمج التشغيلي المجتمعي، دون إهمال البرامج الوقائية والبرامج الموجهة الى الأسرة.

وإذا أُعتبرت جميع الخدمات التي يقدمها القطاع التطوعي خدمات تساهم في عملية دمج المرأة المعوقة في المجتمع تقدر التكلفة المستثمرة في هذا المجال بحوالي ٣ ملايين دولار سنوياً، يساهم الاتحاد العام للجمعيات الخيرية بنسبة كبيرة جدا منها، سواء في البناء المؤسسي لهذه الخدمات أو في إنشاء أو إدارة البرامج والخدمات سنوياً، وخاصة في برامج التدريب والتأهيل للكوادر العاملة مع المعوقين والبالغ عددها ٥٧٨ عاملاً وعاملة.

ورغم حداثة الإهتمام برعاية المعوقين في الأردن وقلة التركيز على برامج الدمج المجتمعي بشكل عام، وللمرأة المعوقة بشكل خاص، فقد قطع ميدان العمل من أجل المعوقين شوطاً لا بأس به في مجال الخدمات والتسهيلات المقدمة للمعوقين والمعوقات والمتاحة لهم. وتبرز هذه التسهيلات في التشريعات القانونية المتعلقة بحقوق المعوقين والمعوقات في مجالات التربية والتعليم والعلاج والتأهيل والتدريب والعمل والفرص والمشاركة في صنع القرار، بالاضافة الى الإعفاءات الجمركية.

وتوفر لهم كذلك تسهيلات بيئية مثل التعديلات في البيئة المادية لأماكن التعليم والتدريب والتأهيل، والتعديل في أماكن العمل والآلات والنظام الوظيفي المستخدم وتكييف المرافق العامة، بالاضافة الى التسهيلات في نظام الاتصالات والإعلام، والتوجه الى احتياجات المعوقات.

وبالرغم من الإنجازات التي تحققت في مجال دمج المعوقين في المجتمع إلا أن هناك العديد من العقبات والمحددات التي تحدد مستوى ودرجة دمج المرأة المعوقة في المجتمع. وتشمل العقبات الاجتماعية كالعادات والتقاليد والأفكار السائدة، والعقبات النفسية التي تعود الى عدم ثقة المرأة المعوقة بقدراتها، وكذلك العقبات الاقتصادية العامة، والعقبات البيئية المادية، والعقبات القانونية والإعلامية، بالاضافة الى العقبات التخطيطية والتنسيقية بين الجهات العاملة في هذا المجال.

ويُستنتج مما سبق أن المرأة المعوقة في الأردن، وإنطلاقا من مبادىء الأديان والتشريعات المتعاقبة والتي هدفت جميعها على التركيز على إنسانية وكرامة الناس جميعا ذكوراً وإناثاً ومساواتهم، ما زالت بحاجة الى الكثير لتحسين الظروف المحيطة بها وتسهيل عملية إندماجها في المجتمع الواسع؛ وأن على جميع القطاعات واجبا في تحمُّل مسؤولية العمل على دمج المرأة المعوقة في المجتمع وحصولها على حقوقها وإتاحة المجال أمامها للمشاركة في بناء المجتمع حسب قدراتها؛ وأن القطاع التطوعي بخلاياه المنتشرة في جميع المناطق هو القطاع المناسب والمؤهل للمشاركة بفعالية في عملية دمج المرأة المعوقة إذا ما توفرت له الإمكانيات والدعم المناسب.

# دور الأسرة
# في الوقاية وفي الاكتشاف المبكر والتأهيل
# ودور جمعيات العمل الشعبي في لبنان(*)

إعداد
رباب شرف الدين

يشرفني أن أشارك في هذا الحدث الهام الذي ينعقد في هذا البلد الطيب، ويصادف انعقاده في هذا العام - السنة الدولية للأسرة. وهذا يتيح لنا فرصة مناقشة مختلف الأبعاد الاجتماعية والاقتصادية والعاطفية التي تعكس وجود فرد من أفراد الأسرة يعاني من الإعاقة وما يفترض أن تكون أدوار الأسرة نتيجة هذه الإعاقة.

إن مفهوم الأسرة، وهي أصغر خلية اجتماعية، يختلف باختلاف الزمان والمكان فهي مفهوم يتكون نتيجة اعتبارات وشروط متغيرة ومتعددة تتحكم فيها الظروف الثقافية والاجتماعية والسياسية والتربوية والاقتصادية. وكل ذلك يرسم الأطر للقيم والأعراف والعادات والتقاليد التي تقوم بدورها بتحديد دور الأسرة، وتوزيع المهام والمرجعيات، بل وحتى العناصر المكونة للأسرة من الناحيتين البيولوجية والاجتماعية.

**أيها الأخوة والأخوات،**

لن أتطرق الى مفهوم الأسرة ومفعولها في كافة المجتمعات، بل سأحاول، انطلاقا من تجربتي الخاصة في بلد شرقي وعربي، أن أسلّط الأضواء على مختلف الجوانب التي أحاطت بأسرتنا ابتداء من لحظة معرفتنا بوجود تأخر في نمو قدرات إبننا الأول، ثم إبننا الثاني.

لا أنكر أننا مررنا، مثل كل الأسر، بالمراحل التي تتحدث عنها مختلف النظريات، ألا وهي:

١- الصدمـــة؛
٢- الإنكار والنفي؛
٣- البحث والتسوق لدى عيادات الأطباء؛
٤- الاستسلام؛
٥- القبـول؛
٦- التعايش ومواجهة المشاكل اليومية؛
٧- الانخراط في مجموعات ضغط؛
٨- تشكيل جمعيات وإقامة مراكز خاصة؛
٩- المشاركة في حملات من أجل التوعية الاجتماعية؛
١٠- المشاركة في تعديل التشريعات والقوانين؛
١١- العمل على تأمين حياة حرة وكريمة ضمن مفاهيم المشاركة التامة والمساواة.

ولا يمكن ربط هذه المراحل ببرزنامة زمنية، إذ ان كل مرحلة من هذه المراحل قد تطول أو تقصر أو تمتد الى فترات طويلة، وتؤثر على مجريات الحياة الأسرية وعلى توازنها وثباتها. ومن العناصر التي لها تأثير على ذلك ما يلي:

(أ) المستوى الثقافي للأسرة؛
(ب) المستوى الاقتصادي - الاجتماعي للأسرة؛
(ج) تطور عناصر المجتمع المدني ومسؤولياته.

**الأم ومراحل الإعاقة**

لا شك أن الإعاقة، بمختلف مراحلها، لها وقع يختلف في شدته بين أفراد الأسرة. ففي المجتمعات الشرقية، نرى أن الأم هي الواجهة الأولى والمباشرة التي تتجه لها الأنظار لحظة تلقي الأنباء، لأنها تصبح من حيث لا تدري، منذ زواجها ودون وجه حق، المسببة لما يحدث، وعليها تحمل الذنب كاملاً من كافة الجهات وعلى كافة المستويات، بدءاً بعائلة زوجها ثم عائلتها ثم الجيران وكل قريب وبعيد. وكم يحلو للجميع أن يتغنى كل ببراعة أبنائه وذكائهم وجمالهم وخفة دمهم ورشاقتهم وطولهم وعرضهم ونجاحهم وتفوقهم وبروزهم ونباهتهم، بالاضافة الى ما يدور من أحاديث في الصالونات والزيارات المتبادلة والحفلات الجامعة. ولا يتوقف الأمر هنا على الانكار والنفي، بل يتعداهما الى الغش والإخفاء والتستر والتسلح بحجج صورية وسطحية وغير واقعية وحتى غير مألوفة. وبالطبع، تبدأ رحلة الزيارات والتسوق بحثا عن الأسماء المناسبة من الفنيين والاختصاصيين المعنيين دون جدوى، مع ما يصحبها من دموع وكآبة ويأس وقنوط وشعور بالإحباط. وتدوم تلك الفترة الزمنية حسب المستوى الثقافي والاقتصادي والعلمي للأسرة بشكل عام وللأم بشكل خاص.

وعندما تصل الأم الى مرحلة التسليم بالأمر الواقع تكون قد حصلت لديها قناعات تتحدد بموجبها أطر تحركها وتفكيرها وهمومها اليومية.

**وأما في مرحلتي القبول والتعايش مع الواقع، فإن طرق التعايش مع الإعاقة والتمرس اليومي تكون كالآتي:**

(أ) تصبح الإعاقة أمراً روتينياً عادياً؛
(ب) تصبح الإعاقة مصدراً للمناكفة والغيرة والتمييز والتمايز؛
(ج) تصبح الإعاقة مصدر إزعاج وبؤرة خلاف وسط العائلة؛
(د) تصبح الإعاقة مشكلة كأداء يتوجّب إبعادها؛
(هـ) يتم البحث عن تجاوب وتفاهم مع الآخرين؛
(و) يتم السعي لإلحاق الطفل أو الطفلة بمراكز تربوية؛
(ز) يتم البحث عن مظلة تشريعية وقانونية للضمان والحماية؛
(ح) يتم السعي الى تأمين حياة مستقلة كريمة بعد توقف الرعاية الأسرية بوفاة أو عجز الوالدين.

سأحاول، بإيجاز، تناول تجربتي كأم لها خبرة في التعامل مع إعاقة الأبناء، بكافة أبعادها، خاصة وقد رزقت بإبن آخر تشبه حالته حالة إبننا البكر (فراس). وكلاهما يتلقيان التأهيل والتربية العلاجية في أحد المراكز التابعة لجمعية أصدقاء المعاقين في بيروت والتي كنا من المؤسسين لها ويترأسها زوجي حاليا.

وسأحاول، بعد سرد تجربتي، تحديد مدى قدرة الأهل على التعامل مع إعاقة أطفالهم بشكل خاص.

لا أنكر عليكم أن معرفتنا كأسرة، وكأم خاصة، بوجود اعاقة لدى ابننا الأول كانت صدمة قوية إذ انني كنت في مقتبل العمر ومثقلة بالأحلام الوردية والمستقبل الزاهر، وكنت قد أعددت المناهج والبرامج وحتى المدرسة، التي كان من المفترض أن يلتحق بها ابني البكر.

لقد اكتشفت الإعاقة لدى إبني الأول في وقت متأخر، إذ ان جميع الأطباء والاختصاصيين الذين شاهدوا ولدي في العامين الأولين من طفولته، كانوا قد أجمعوا ان طفلي ينمو ببطء، وما علينا إلا تزويده بالمقويات والأغذية المناسبة. ورغم جميع تلك الاجراءات لم يطرأ أي تحسن ملحوظ على نمو إبننا. وبعد التشخيص النهائي أكتشف وجود الإعاقة، دون تمهيد أو إستعداد نفسي من شأنه أن يخفف من قوة الصدمة. وتساءلت مع زوجي لماذا يحدث لنا هذا الآن ونحن في مقتبل العمر؟، لماذا نحن بالذات؟، ما الذي اقترفناه؟ ... وتنهال الأسئلة من كل حدب وصوب وعلى كافة الأصعدة. أهذا نتيجة حسد، أم عقاب، أم أن أحداً ما كتب لنا (كما يقولون).

نعـم، قالوا لنا إنها مشكلة وراثية، وبالطبع لا يمكن أن يأتي عامل الوراثة إلا من الأم ... في مجتمعنا؛ أليست هي من الجنس الآخر، أو بالأحرى، من الطبقة الثانية في المجتمع وهي تحمل وزر الوراثة والتربية والتعليم والترشيد. فإذا ما برز وتميَّز طفل ... فهذا ابن أبيه وهذا الشبل من ذاك الأسد، أما اذا ما تأخر الطفل في النمو أو المدرسة أو التربية فمن المؤكد أن وراء ذلك أم مهملة وجاهلة.

ولم تطل فترة مكوثنا في تلك المرحلة، إذ أن كون زوجي طبيبا سرَّع في قدرتنا على قبول الإعاقة لدى طفلنا. وبدأنا بالتكيف، ومن ثم انتقلنا الى مرحلة تشكيل وتنظيم قوة ضغط بمساعدة العديد من الأسر المشابهة وتمكنَّا من تأليف عدة جمعيات وافتتحنا عدة مراكز للرعاية النهارية ونسعى الآن لتكريس تجاربنا والتعامل مع أجهزة الإعلام وبحث التشريعات لتعديلها.

**ما هو الدور الذي يمكن أن تقوم به الأسرة، والأم بشكل خاص للتعامل مع مشكلة الإعاقة وقاية وتأهيلاً وتشغيلاً ودمجاً؟**

فيما يتعلق بالوقاية التي يجب أن تتناول الاجراءات التي تحد من حدوث الإعاقة لدى الأطفال، فهي تنقسم الى عدة أنواع من بينها:

(أ) عوامل وراثية يمكن تحديد البعض منها قبل الزواج؛
(ب) عوامل تحيط بفترة الحمل؛
(ج) عوامل تحيط بفترة الوضع والولادة؛

(د) عوامل ما بعد الولادة وخلال مراحل الحياة.

العوامل الوراثية:

ليس بالإمكان الإحاطة بهذا الموضوع من كافة جوانبه ولكن هناك ثوابت هي:

(أ) احتمال حصول الإعاقة لدى الأطفال كلما كانت القرابة العائلية أكبر بين الزوجين؛

(ب) احتمال حصول إعاقة وراثية لدى الأطفال في حال وجود إعاقة في الأصول والفروع الأسرية من جانب الأم أو الأب؛

(ج) لمواجهة ذلك علينا التعامل مع المفاهيم السائدة في مجتمعاتنا بالشكل المناسب لنقلل قدر المستطاع من حصول زواج الأقارب الذي كان ولا يزال شائعاً جداً في مجتمعاتنا وخاصة العشائرية منها؛

(د) أما في حال وجود أقارب للأم أو للأب مصابين بإعاقة، واذا كان السبب محدداً، فيمكن اكتشاف الاعاقة قبل حدوثها بمراحل عبر العديد من الفحوص المخبرية الميسرة في كثير من بلدان العالم وفي عدد من الدول العربية ... لكن هناك الكثير من الأمور الواجب مراعاتها اذا ما اكتشفت الاعاقة لدى الجنين، وخاصة في المرحلة الثانية من الحمل، وبالتحديد بعد الأسبوع السادس عشر من الحمل، علماً بأن هناك أبحاثا جدية ومتقدمة تجري في مجال الهندسة الوراثية، لتعديل مواقع الجينات الموروثة.

العوامل الحاصلة خلال فترة الحمل والتي يجب الحرص على تجنبها:

(أ) التغذية المتوازنة والمناسبة للأم الحامل؛
(ب) عدم تناول الأدوية إلا بعد استشارة طبية متخصصة؛
(ج) متابعة الحمل لدى الأطباء المتخصصين في شؤون الحمل؛
(د) عدم تناول المشروبات الكحولية؛
(هـ) عدم تناول المخدرات؛
(و) عدم التعرض للأشعة السينية؛
(ز) عدم التدخين؛

(ح) الحرص على تجنب التعرض للأمراض المعدية وخاصة الحصبة الألمانية (ومن الأفضل التلقيح قبل الزواج)، والتوكسوبلازمور، وفيروس "Herpes"، وفيروس "Cytomegallic"، الذي يشبه، من حيث التكوين، فيروس نقص المناعة البشرية (HIV) المسبب لمرض الايدز، وخاصة خلال الأشهر الثلاثة الأولى من الحمل؛

(ط) العلاج والمراقبة الطبية الدائمة اذا كانت الأم مصابة بالسل أو السكري أو أمراض القلب والشرايين أو الأمراض التي تنتقل مباشرة الى الجنين؛

(ي) الحرص على عدم تناول المواد السمية أو الملوثة أو الأدوية قديمة الصنع (وهو أمر شائع في بعض الدول النامية نظراً لانخفاض كلفتها).

العوامل الحاصلة حول فترة الحمل:

(أ) متابعة الفحوص الدورية تحت مراقبة طبية صارمة؛

(ب) مواجهة التغيرات الصحية بالوسائل الطبية لاسيما وأن العادات والتقاليد السائدة في الدول العربية مازالت تعزز دور القابلات على حساب الطبيبات والأطباء، وما زالت تعتمد المنزل أو العيادة كمركز للتوليد بدلا من المستشفى، وما زالت تشجع على الأخذ بمشورة الصديقات والجيران والجدات ... وما الى ذلك من استعمال وسائل علاجية تفتقد الى المصداقية العلمية المجردة ... وترك الوسائل العلمية الحديثة؛

(ج) إن الولادة في المستشفى تخفف بشكل كبير جدا من حدوث اعاقات لدى الأطفال. فهناك عدد لا يحصى من الحالات الصحية الطارئة التي يعتمد علاجها على أمور بسيطة ورخيصة، يمكن التزود بها إذا تمت الولادة في المستشفى. فهي تمنع حدوث الإعاقة لدى الأطفال (بتوفير الأوكسجين والحاضنات الكهربائية وكافة الوسائل التي يمكن عن طريقها حماية المواليد الجدد من أي طارئ، ومعالجة أية تشوهات خلقية للتخفيف من حدتها والحد من معيقاتها)؛

(د) العناية بحياة الأطفال وخاصة في سنينهم الأولى:

(١) الحرص على التحصين وفق البطاقة الصحية وبشكل دوري؛

(٢) الحرص على التغذية من الثدي لأطول مدة ممكنة (وبرهنت الأبحاث أن ذلك يؤمن الحماية والمناعة للطفل اضافة الى تعزيز القدرات الحركية والحسية والذهنية)؛

(٣) الحرص على التغذية الكاملة والمناسبة للطفل؛

(٤) العنايـــة الصحيـــة؛

(٥) الإتزان في تربية الطفل عبر المثيرات الحسية والعاطفية وكافة أنواع النشاطات ومواكبة نمو الطفل على جميع الأصعدة؛

(٦) القدرة على الاكتشاف المبكر لأية عوارض أو انحرافات، صحية كانت أم حركية أم ذهنية أم حسية والحرص على استشارة الأخصائيين للتزود بالمعلومات والوسائل التي يمكن من خلالها التدخل المبكر تجنباً لتفاقم تلك الانحرافات ... وتحولها الى معيقات تعجز الأطفال الى الأبد؛

(٧) إيلاء أقصى الاهتمام لتربية وتنشئة الطفل في سنينه الخمس الأولى لإيصاله الى الاستقلالية التامة في تصريف شؤونه الحياتية اليومية؛

(٨) مشاركة المدرسة والعاملين التربويين والاجتماعيين في معالجة مشاكل الأطفال.

**دور الأسرة / الأم في التدخل المبكر والتأهيل والتربية:**

للأم في المراحل المبكّرة للإعاقة دور أساسي ومصيري. ومن واجبها أن تراعي الأمور التاليـــة :

١- التعرف عن كثب على مدى الاعاقة لدى طفلها وانعكاسات تلك الاعاقة على قدرة الطفل في تصريف شؤونه اليومية.

٢- تحديد مدى حاجات الطفل ونوعيتها وكميتها، لأن هناك اختلاف بين قدرات الأفراد واحتياجاتهم.

٣- التعرف تدريجياً على الإطار المنهجي لتطوير قدرات المصاب وتحديد أهداف مرحلية والعمل ضمن خطط ونشاطات مدروسة تتلاءم مع مراحل التطور الطبيعي للأطفال ومن ثم الناشئة والشباب.

٤- الإستقصاء بشكل دؤوب وحثيث عن المعلومات والاكتشافات الحديثة عبر الوسائل المتاحة، كالمطالعة، ومشاهدة البرامج التلفزيونية، واستغلال الموارد الاعلامية المناسبة للتزود بالمستجدات والخبرات، وتسجيل ما يمكن تسجيله وتوثيق ما يمكن توثيقه وذلك للاستفادة شخصيا منه وتزويد الآخرين به.

٥- استغلال كافة الوسائل المحلية المتاحة وخاصة فيما يتعلق بالمعدات والألعاب التربوية والتأهيلية المتيسرة في المنزل وفي البيئة السكانية قبل التفكير في شراء المواد والتجهيزات والمعدات المسوقة تجارياً والتي كثيرا ما تكون باهظة الثمن.

٦- الحرص على مناقشة البرامج المقترحة من قبل الفنيين وادراك مدى الفائدة منها. فلا يمكن للأم أن تتحمس للعمل دون الاقتناع والتفهم من خلال البحث عن بدائل ووسائل تبحث مع ذوي الخبرة، وكثيراً ما تتمكن الأم من اقناع الفنيين بأساليب بسيطة.

٧- إن وجود المصاب في المنزل، أطول مدة ممكنة، خاصة خلال سنينه الخمس الأولى يجعل من دور الأسرة، والأم بالذات، أمراً مصيرياً، ولاسيما في غياب أية برامج لرياض الأطفال مخصصة للأطفال المعوقين في دول المنطقة في معظم الأحيان.

٨- ان المؤسسات والمراكز وجمعيات العمل الشعبي في مجال التأهيل لا يمكن أن تحل محل الرعاية الأسرية مهما بلغت براعة الفنيين والعاملين الاجتماعيين فيها. فهذه المؤسسات التأهيلية ليست سوى مواقع مرحلية ومؤقتة لإعداد المصابين للمشاركة التامة والمساواة بالتعاون مع الأهل، لأن مكان المعوقين في النهاية هو المجتمع المحيط، بحيث يشارك كل فرد من أفراد المجتمع بامكانياته في عملية استيعاب المعوقين ومشاركتهم. أما اذا لم تقم الأسرة، والأم بشكل خاص، بواجباتها تجاه ابنائها فلا يمكنها أن تنتظر من الآخرين أن يعيروا أي انتباه لأبنائها المعوقين.

## دور جمعيات العمل الشعبي

يختلف دور جمعيات العمل الشعبي في مجال التأهيل في دول المنطقة عن غيرها في الدول المتقدمة، إذ أنها تشبه تلك التي أقيمت في تلك الدول خلال العقود الماضية من حيث أشكال تنظيمها ومهماتها.

ومن هنا، يجب أن يشمل عمل الجمعيات في دول المنطقة ما يلي:

١- مراعاة غياب التشريعات وتدني دور القطاع الرسمي فيما يتعلق بالإعاقة.

٢- مراعاة مدى تدني الوعي العام تجاه قضية الإعاقة.

٣- أن يهدف العمل الى تطوير المجتمع على كافة الأصعدة المادية والمعنوية. فمن خلال تطوير المجتمع وتأهيله تسهل عملية العناية بالمعوقين وذوي الحاجات في المجتمع، وبهذه الطريقة يمكن أن تظهر الأولويات الحقيقية في حاجات المجتمع وخاصة في الدول النامية، وبالتالي تنخفض تكلفة التأهيل نظراً لمشاركة الجميع وتوزع المسؤوليات على أفراد البيئة السكانية والمجتمع المحلي.

وكلما اشتركت جمعيات العمل الشعبي في مجال التأهيل في هذا الدور سواء كانت جمعيات دينية، أو سياسية، أو علمية، أو طبقية (لإبراز طبقات وأفراد في المجتمع على حساب الإعاقة)، أو تأهيلية اجتماعية يشارك فيها المعوقون وأسرهم، كلما كان هذا الدور شاملاً وملائماً لقدرات أفراد المجتمع المحلي، وكلما كان عمل تلك الجمعيات فاعلاً ومتطوراً وهادفاً.

ولا شك أن دور الأهل، وخاصة أهالي الأطفال المعوقين عقلياً، كان وما يزال هو الدور الأبرز في تغيير صورة المعوق عقلياً في الجمعيات، ويشهد على ذلك ما حصل أثناء العشرينات في دول أوروبا الغربية، حيث كوّن الأهالي جمعيات وأسّسوا مراكز لتأهيل هؤلاء الأطفال. أما في المنطقة العربية، فهناك شواهد تاريخية تدل على أن العرب كانوا سبّاقين منذ القرن التاسع

الميلادي وحتى القرن التاسع عشر، في إقامة مؤسسات الرعاية ضمن ما يسمى بالمستشفيات العامة التابعة للدولة، ولكن ذلك تدهور بشكل ملحوظ ابتداءً من القرن السادس عشر.

وكما تعلمون فقد كان نمط الرعاية المؤسسية شائعا، وهي الرعاية الدائمة للمعوقين داخل أبنية محاطة بحدائق، حيث يدخل المعوقون هذه المؤسسات ولا يخرجون منها. ناهيكم عما يحصل بين تلك الجدران من أمور وممارسات لا ترقى الى أدنى المعايير الانسانية. ومن الأمثلة على ذلك ما يلي:

(أ) حشد أعداد كبيرة في أبنية غير مؤهلة صحياً من حيث المساحة؛

(ب) وجود أنظمة صارمة يسهر على تنفيذها أشخاص غير مؤهلين؛

(ج) الكساء والغذاء والنظافة وغير ذلك من أمور حياتية جوهرية تجعل الحياة فيها أسوأ بكثير من حياة السجون؛

(د) تفشي الأمراض واعتماد أساليب طبية تعسفية؛

(هـ) ارتفاع التكاليف المادية مقابل تأمين الخدمات في تلك المؤسسات؛

(و) عزل هؤلاء الناس وتهميشهم وهدر طاقاتهم ودفنهم أحياء لأطول مدة من الزمن، وهذا ما دفع الأمم المتحدة لإعلان عام ١٩٨١ "سنة دولية للمعوقين"، والفترة ١٩٨٣-١٩٩٢ "عقدا دوليا للمعوقين"، وأقرت برنامج العمل العالمي الذي التزم به الكثير من الدول.

أما الآن فقد برز دور جمعيات العمل الشعبي الأهلية في مجال التأهيل في لبنان وبشكل خاص في السنوات العشرين الأخيرة. فهناك عدة أشكال من الخدمات لا تتعدى طاقة استيعابها ١٥٠٠ حالة في مجال التخلف العقلي، أي ٥٠ في المائة من الأطفال اللبنانيين المصابين، وهي موزعة كالآتي:

١- رعاية دائمة داخل المؤسسات، وذلك طوال الحياة: ٥٠ في المائة.
٢- رعاية داخل المؤسسات، مع فرص أسبوعية: ٢٠ في المائة.
٣- رعاية داخل المؤسسات حتى سن العشرين: ٣٠ في المائة.
٤- رعاية نهارية بنسبة ٥٠ في المائة موزعة كالآتي:

(أ) رعاية نهارية بمشاركة الأهل: ٣٠ في المائة؛

(ب) رعاية اجتماعية في عدة أشكال أهمها الزيارات المنزلية وتوجيه الأهل بكيفية التعامل مع أطفالهم والقيام برحلات ومناسبات اجتماعية: ٥ في المائة؛

(ج) دمج مدرسي لذوي الحاجات الخاصة، ولاسيما ذوي الإعاقة البسيطة والمتوسطة: ٥ في المائة؛

(د) التأهيل المهني ثم العمل في ورش محمية، أو العمل ضمن البنية السكانية: ٥ في المائة.

(هـ) تأمين سكن مستقل وحياة حرة كريمة: ٥ في المائة.

وما زال عمل الجمعيات في لبنان في أولى مراحله، وتقدم تلك البرامج والخدمات الى ما لا يزيد على ١٠ في المائة من معوقي المنطقة. أما باقي المعوقين فهم لا يستفيدون من أية فرص تأهيلية، علماً بان العبء يقع بشكل أساسي على الجمعيات الأهلية ودور الحكومات ما يزال ضعيفا في معظم الدول العربية.

ويوجد تفاوت كبير في كمية ونوعية الخدمات المقدمة من الناحية العلمية والفنية نظراً الى تدني الموارد المادية والأكاديمية والصحية والتشغيلية لدى معظم جمعيات العمل الشعبي. ولذلك لا توجد في هذه الجمعيات، في معظم الأحيان، برامج ومناهج وخطط عمل ومراقبة ومراجعة وتطوير. والجمعيات تفتقر الى سياسة واضحة والى استراتيجية عمل خاصة فيما يتعلق بتجهيزها مادياً وبشرياً. ويندر وجود فنيين واختصاصيين متحمسين ومندفعين للعمل في مؤسسات طوعية وخيرية، إذ أن كل الجمعيات العاملة في دول المنطقة، تقريبا، هي جمعيات خيرية تعتمد التبرعات والمناسبات الدينية موردها الأساسي، ونادراً ما تتم تغطية النفقات بهذه الطريقة. وفيما يتعلق بهذه الجمعيات، يلاحظ ما يلي.

١- أن معظمها يوجد في المدن الكبيرة والمناطق المكتظة بالسكان، ويندر وجودها في المناطق الريفية والنائية.

٢- لا توجد سياسات رسمية واضحة أو تشريعات وطنية، بل كلها أمنيات وحلول سطحية.

٣- أما من ناحية تمثيل أهل المعوقين، فإن الهيئة الوطنية لرعاية المعوقين في لبنان قد تشكلت من ممثلين عن القطاعين العام والخاص، ولا يوجد فيها تمثيل للمتخلفين عقلياً أو أهلهم، ولا يوجد سوى اتحاد واحد لجمعيات الاعاقة في لبنان.

٤- هناك نقص فادح في عدد الفنيين العاملين في مجال التربية الخاصة وخاصة في مجال التأهيل الذهني وعلاج النطق.

٥- نشأت مؤخراً اتحادات لجمعيات أهالي الأطفال المعوقين في الأردن وتونس ولبنان مهمتها أن تكتل الجهود لمواجهة العقبات، ولكن هذه الاتحادات مهددة بشكل دائم، خاصة وأن الجمعيات الناجحة لا تجد مصلحة في الانضمام لهذه الاتحادات، خوفا من أن تفقد مبرر وجودها.

إننا نتطلع الى اليوم الذي يظهر فيه منظور جديد لجمعيات العمل الشعبي حتى يكون عملها أشمل، بحيث تؤهل المجتمع لإستيعاب الأفراد ذوي الحاجات الخاصة وتساهم في عملية دمج المعوقين في كافة المراحل وعلى كافة الأصعدة ضمن عملية اجتماعية وثقافية شاملة.

وهكذا نرى مدى أهمية دور أفراد الأسرة، وبخاصة الأم، في مواجهة القضايا الاجتماعية الشائكة من خلال العمل على تنمية قدرات أطفالهم مشاركة منهم في تطوير مجتمعاتهم.

**توصيات انطلاقاً من تجربتنا في لبنان:**

١- تشجيع أسر الأطفال المعوقين على التلاقي والتعرف على بعضها البعض لتشكيل تنظيمات وقوى ضاغطة، تمكنها من إيصال قضيتها الى كافة أفراد المجتمع، وإيلاء الإعاقة الأهمية التي تستحقها.

٢- التوجه الى جميع التنظيمات الاجتماعية لإشراكها في عمليات التوعية والإرشاد.

٣- التوجه الى القطاعات الإعلامية لتوضيح أسباب الاعاقة وسبل اكتشافها ووسائل التعامل معها، وشرح مدى أهمية دور كل فرد من افراد المجتمع في معالجة مشكلة الاعاقة.

٤- التوجه الى الجمعيات الثقافية والاجتماعية والدينية والصناعية والتجارية والنقابية والى الرابطات والمعاهد بهدف رفع الحيف ووقف التمييز ضد المرأة، وخاصة الأم، وإبراز دورها كشريك كامل في بناء المجتمع.

٥- مناشدة المجتمع الدولي، بمناسبة السنة الدولية للأسرة، أن يكرس حقوق المعوقين وأهلهم وأن يسهر على تطبيق ما اتخذ من توصيات وتشريعات ومبادئ. فالقرارات التي تُتَّخذ كثيرا ما تكون على درجة عالية من روعة اللفظ وعمق الإحساس، ولكنها قلما تكون على نفس المستوى من حيث التطبيق.

# THE ROLE OF THE FAMILY AND POPULAR ACTION ASSOCIATIONS IN DISABILITY PREVENTION, EARLY DETECTION AND REHABILITATION IN LEBANON

## SUMMARY

RABAB CHARAFEDDINE

The concept of the family varies with time and from country to country, and depends on cultural, social, political, educational and economic factors as well as customs and traditions which in turn determine the role of the family and the tasks of each one of its members. I will try in this paper to shed light on the various problems which my husband and I faced from the moment we learned that our eldest son and his younger brother were growing at an abnormally slow pace.

Having disabled children in the family affects the other members of the family, and especially the mother because, in Middle Eastern societies, she is always considered the origin of the problem and has to shoulder full responsibility for it as everybody, including her husband's family, her own family, the neighbours and relatives lay the blame for that on her. The initial shock was followed by denial and even self-deceit and attempts to hide the truth by resorting to fallacious arguments. The physicians and specialists we consulted were unanimous in their diagnosis that our son was a case of abnormally slow growth and prescribed restorative drugs and appropriate diet. But as no improvement occurred, we went back to the physicians, who reached the conclusion that a hereditary factor was involved. This revelation was followed by a period of despondency and despair, as in Middle Eastern societies hereditary factors cannot be attributed but to the mother, who has to assume responsibility for them as well as for the education and guidance of her children. If the son or daughter performs well at school, his or her good performance is ascribed to the father, but if his or her growth is abnormally slow or his performance at school is poor, then it will be ascribed to a neglectful and ignorant mother. The fact that my husband is a physician enabled us to go quickly through that stage and accelerated our acceptance of our child's disability, and we started adapting to the situation. Then we constituted a pressure group with other families affected with the same problem and established associations and several day care centres for disabled children and are now concentrating our efforts on convincing the media to contribute in awareness-building about disability and on amending legislation.

The prevention of disability must take into account hereditary factors, as the incidence of disability is higher in kinship marriages and also when the mother or father has relatives affected with disability. Disability in this case can be detected through laboratory tests.

Important requirements during the pregnancy period include: a balanced diet for the mother; taking medicines only on prescription; follow-up of pregnancy; abstaining from alcohol, drugs and smoking; avoiding exposure to X-rays, and vaccination against contagious diseases, as well as continuous medical follow-up if the mother is suffering from consumption or cardiovascular diseases or diseases that can be transmitted directly to the infant.

Other important requirements during pregnancy include periodical check-ups and the use of modern medical remedies, as tradition in Arab countries is still promoting the role of midwives and the advice of friends and neighbours at the expense of the physician and the hospital, since deliveries are still carried out at home, not at the hospital, and old remedies are used instead of modern scientific remedies. Delivery at the hospital decreases tremendously the incidence of disability among children, as the modern equipment at their disposal such as incubators enables them to alleviate the effects of problems at birth.

Children should receive the care they need, especially during infancy, which includes vaccination, breast-feeding, appropriate diet, health care, early detection of any abnormality and consultation with specialists in order to prevent such abnormalities from becoming permanent disabilities.

The role of the mother in early intervention, rehabilitation and education is crucial and includes the following tasks: determining the degree of the disability the child is affected with and the impact of that disability on his/her ability to conduct daily activities; drawing up a programme to develop the capabilities of the child, determining the goals to be reached by stages and drawing up carefully studied plans of action consistent with the natural development of the child; keeping abreast of new developments related to the treatment of disability and making use of new methods and equipment; making use at home of all the locally available educational and rehabilitational equipment and games; and discussing the programmes put forward by experts and evaluating their usefulness. The role of the family, and especially of the mother is crucial, particularly during the first five years of the life of the disabled child, as there are no nursery schools in the region which accept disabled children. However, the institutions, centres and associations engaged in rehabilitation cannot replace family care as their task is to ensure full participation of the disabled in society in cooperation with the family.

The role of the associations engaged in the rehabilitation of the disabled in the region should take into account the absence of legislation and the limited role of the public sector in that field, as well as the low level of public awareness about disability, and should aim at developing society on all levels by concentrating on its real priorities. The participation of all sectors of society and the distribution of responsibilities among them will help in reducing the cost of rehabilitation. The more comprehensive and consistent with the capabilities of local communities the role of the

associations engaged in rehabilitation, the more the activities of those associations will be effective and appropriate.

Associations for the rehabilitation of the disabled were created in Europe in the 1920s. In the Arab region, such institutions were found within public hospitals as early as the ninth century and till the nineteenth century, but the situation has deteriorated markedly since the sixteenth century. Institutional care was mainly characterized by overcrowding, harsh regulations, poor clothing and food, lack of hygiene, spread of contagious diseases and total marginalization of inmates. But today there are several kinds of private associations engaged in rehabilitation in Lebanon, most of which were founded during the last 20 years. The total capacity of these institutions does not exceed 1,500 mentally retarded children. The activity of these associations is still in its early stages as they are now providing their services to 10 per cent of the disabled children in the region; the remaining 90 per cent are deprived of any rehabilitation opportunity. The role of the public sector in this field is still very limited in most Arab countries.

There are a lot of discrepancies in the quantity and quality of services provided, as most of these associations have only limited human and material resources. Therefore, they do not have, in most cases, programmes or plans of action. Most of them are found in big cities and there is no clear official policy or national legislation concerning them. The disabled and their families are not represented in those associations. There is a severe shortage in the number of specialists in rehabilitation of visually impaired persons and deaf-mutes.

## RECOMMENDATIONS

1. Disabled children should form pressure groups to present their case to all sectors of society and get the attention they deserve.

2. All social institutions should participate in the awareness-building process.

3. The media should explain the causes of impairment and ways of detecting and addressing them, and the importance of the role of each member of society in tackling the issue of disability.

4. Cultural, social, religious, industrial and labour organizations should be urged to stop discriminating against women, and especially mothers, and should point out the importance of her role as a full partner in the building of society.

5. An appeal should be addressed to the international community on the occasion of the International Year of the Family to recognize the rights of the disabled and their families and to ensure that the recommendations, legislation and principles adopted are applied.

# CHILDHOOD DISABILITY: CAUSES AND ROLE OF THE FAMILY IN PREVENTION, EARLY DETECTION AND REHABILITATION

*Nazek Nosseir*

*Our children among us are likened to our hearts walking on earth,*
*where a wind on them is heightened,*
*sleep would not come forth.* [Ancient Arabic poetry]

## Introduction

The birth of a child brings joy and happiness to its parents. It is an event that is celebrated by members of the family as well as by friends and neighbours. From time immemorial and until today, reproduction has been and continues to be one of the important functions of the family. It is a responsibility that is assumed with pride. To watch one's own children grow and mature into adulthood is an effort that parents gladly undertake. This is true among the different cultures of the world, and certainly is true of our culture here in the various countries of this region. However, it is also true that for various reasons children may be born with an impairment which renders them unable to perform like other children of the same age and sex. Sometimes, this impairment is acquired after birth but all the same it hinders the child from performing in the same way as his/her counterparts of the same age and sex. Such situations cause a lot of concern, stress and pain to the parents. Sometimes, they may even lead to anger, rejection and denial or refusal to accept and cope with the situation. Such reactions have been documented, and, naturally, are expected. In addition, childhood disability is costly to the community and the nation as a whole. Therefore preventive measures should be taken. Early detection and intervention should be employed, and rehabilitation programmes should be provided in order to equalize the opportunities of disabled children to become productive members of society.

The objectives of this paper are: to address the issue of childhood disability mainly with respect to identifying the main causes and to review the role of the family, particularly the mother, in disability prevention, early detection, treatment and rehabilitation of the disabled child. This will be followed by review and conclusions. It should be noted that the review will be relevant mainly to the countries of the ESCWA region.

## A. CAUSES OF CHILDHOOD DISABILITY

In this section, I will address the various factors that may contribute to the occurrence of impairments in children. Some of these impairments, if not attended to promptly, would leave a child unable to perform like other children of the same age and sex; therefore the impairment turns into a handicap. The main concepts used for this review will be defined. For this purpose the definitions proposed by the World Health Organization have been adopted (1).

### *1. Impairment*

Any loss or abnormality of psychological, physiological, or anatomical structure or function.

### *2. Disability*

Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

### *3. Handicap*

A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.

Thus it is clear that impairments may affect children even before they are born, during birth or after birth. The variations of impairments are due to a multiplicity of causes. Some of these causes act independently, others interactively.

However, for purposes of discussion in this paper, I will group the various likely causes of childhood disability into three main groupings. Causes in each of these groupings are likely to impair the child during a particular time period of his/her life cycle.

(a) Before birth

Children may suffer impairments leading to disabilities at conception or before they are born because of one or more of the following causes:

☼ Endogamous marriages, particularly marriages between cousins, are popular in all Arab countries. As a matter of fact, this type of marriage is preferred by both the well-to-do and poorer families.

Many studies have shown that a large proportion of children born from these marriages suffer from impairments resulting from genetic disorders. These impairments may affect the sensory, physical or mental abilities of the child. Though the married couple may look perfectly normal, they could still be carriers of certain genetic disorders that affect their offspring (2).

☼ Babies born with a low birth-weight are easily susceptible to various organic impairments leading to disabilities. Low birth-weight babies are born more preponderantly to very young, or relatively old mothers. Low birth-weight is also more prevalent among high birth-order babies, and among babies born at short birth intervals after the preceding birth. All of the above-mentioned factors are characteristic of high fertility populations. Most of the countries in our region are characterized by high fertility populations. Consequently, it would be expected that a large proportion of the babies are born prematurely or with low birth-weights which render them vulnerable to various types of disabilities.

☼ The general malnutrition of women which arises from a lack of knowledge or ignorance of the need for additional food during pregnancy may lead to the birth of babies with poor health or with impairments that may affect the mental and physical development of the child. For example, women suffering from iodine deficiency may bear cretins (3) who will suffer from mental retardation.

(b) During birth

Children may be exposed to traumatic experiences during birth that leave them impaired and unable to lead a healthy life. A large number of births still take place at home and are attended by untrained traditional midwives. Many of these homes lack sources of clean running water and other safe sanitary facilities. In such unhealthy environments, newborns are likely to be exposed to diseases that restrain their physical and mental growth. The presence of untrained birth attendants does not help to improve the situation. Mishandling the newborn during childbirth may result in injury and permanent deformity of the child.

(c) After birth

Most childhood disabilities occur after birth. The various factors that cause disability among children are too numerous to be listed. However for the purpose of this paper, these factors are grouped into four areas:

1. Factors related to the nutritional intake of the child. In the early months of the child's life, breast-feeding has been recommended as the most important source of nourishment. The quality and quantity of the mother's breast milk are very much affected by her own nutritional status. Mothers who suffer from malnutrition are unable to provide their children with sufficient, high-quality breast milk, which

may impair the child's immune system, and expose him/her to illness. Deficiencies in protein, iron and vitamin D are common among mothers of young children.

By the time the child is 4-6 months old, supplementary food of the proper type should be given. For one reason or another, a large proportion of children do not get that food and thus are found to suffer protein calorie deficiency. In general, poor weaning practices, frequent diseases, and meagre meals leave many pre-school children undernourished or anaemic. In such cases, children become unable to learn when they start school.

Malnourishment of children also stunts their growth. Vitamin D deficiency makes children develop rickets (4), while vitamin A deficiency causes blindness.

One can never underestimate the importance of adequate nutritional intake for the development of a sound body and mind.

2. Factors related to poverty. Poverty is a condition that is experienced by large numbers of people in the developing countries including countries of this region. Poverty is manifested in different ways that are related to the disability, particularly childhood disability. It is manifested in malnutrition, which as mentioned above, is considered to be one of the main causes of childhood disability.

Poverty is often associated with unsanitary living conditions, the unavailability of safe drinking water and lack of proper means of garbage disposal. All of these factors contribute to the widespread incidence of communicable diseases, which leads to poor health or impairment. An absence of hygienic practices is closely associated with diarrhoea-related diseases, which are among the major causes of stunted growth and even early death among children.

It has been observed that frequent illnesses are a threat to a child's nutritional health and long-term growth: they reduce appetite; they inhibit the absorption of food; they consume calories in fevers and in fighting the disease; and they drain away nutrients in vomiting and diarrhoea. When such illnesses strike frequently, the child is steadily pushed into a downward spiral of malnutrition and ill health. And it is this spiral, rather than any individual cause, which results in many children failing to grow to their full mental and physical potential (5).

Another manifestation of poverty is the early exploitation of children in child labour both at home and in the workplace. Children can be abused and it deprives them from pursuing their education. They either do not go to school or drop out early, which leaves them illiterate. Illiteracy and disability have a reciprocal relation in the sense that illiterates are often ignorant of the ways and means that help to improve their status economically, socially and psychologically—a situation that may lead to

disability. Disabled individuals often end up illiterate and are thus restricted from participating in rehabilitation and training programmes.

3. Accidents. A large number of disabilities result from accidents on the road, at work or at home. Such accidents may leave the child with an amputated limb or otherwise disabled. Accidents happen to children when they are left unattended at home or in the streets. Quite often mothers are over-exhausted and depleted of energy and therefore fail to watch their children carefully, which exposes them to accidents.

In many developing countries, roads are built to accommodate large numbers of vehicles. Quite often such vehicles are not equipped with safety devices, thus leading to accidents, with children being the primary victims. Furthermore, children who are sent to work at an early age and before they receive adequate training may be hurt while they are using machinery.

4. Wars. Unfortunately, several countries in the world today are suffering from wars. It is thought that it is only adult men who get hurt in wars; however, modern warfare and modern war equipment make no distinctions between men, women and children. Modern warfare is destructive to everybody and everything. Many of those who survive a war are left physically and psychologically disabled.

## B. Role of the family in coping with childhood disability

An analysis of the major causes of childhood disability clearly shows that many of these causes are socio-culturally rooted. It is socially and culturally expected that the family, particularly the mother, is the one who tends to and takes care of the sick and/or disabled members of the family. Therefore in this section of the report, I will focus on the role of the mother in prevention, early detection and intervention in childhood disability, as well as the rehabilitation of the disabled child. Obviously it is assumed here that mothers will not operate in a vacuum, but rather that there will be support, cooperation, collaboration and participation of other family members, as well as from all segments of the society. Clearly disability involves a cost not only to the disabled individual, but also to the family, community, and the nation at large. The cost is psychological and social as well as economical.

### *1. Prevention of disability*

Given the cost involved in dealing with childhood disability, especially the emotional cost to the mother of the disabled child, it would seem only natural that women would spare no effort to minimize the chances of having a disabled child—and hence to take preventive measures.

As mentioned above, however, endogamous marriages, and particularly marriages of cousins, have contributed to a high incidence of various hereditary

impairments in children born into these families. Since such marriages are common and since the practice is expected to continue in the countries of the region, women should seek genetic counselling, preferably before marriage, but if not, then at least before pregnancy or during pregnancy. Prenatal care of pregnant women helps to prevent impairments that can occur in the unborn child.

Scientific research has identified certain genetic disorders that can develop into impairments, and that can be detected by means of neonatal screening. If detected early enough, these disorders can be eliminated simply by putting the new-born child on a special diet for a certain period.

Other preventive measures that could be taken by mothers include refraining from getting pregnant at very young ages and also during the latter part of the reproductive period, to avoid possible impairments that may occur to that offspring. Children born to women in these age groups are more likely to suffer various disabilities than children born to women in other age groups. In relation to this point, women should allow ample spacing between births. On the one hand, spacing allows the continuation of breast-feeding for an adequate period—a practice that should be encouraged for the health of the child. On the other hand, spacing of births allows the woman to regain her strength to cope with the subsequent pregnancy.

In order to prevent disabilities in children, women should eat a balanced diet, especially during pregnancy and when they are breast-feeding. A balanced diet is not necessarily an expensive one, however; women should be made aware of local food items that are rich in iron, protein, vitamin A and vitamin D, in addition to the importance of an iodized salt supply.

Breast-feeding and proper weaning practices should be encouraged. Women should be made aware of the appropriate ages at which to introduce food supplements to the child. Malnutrition among children has been observed in later infancy and early childhood years—a time when the physical and mental abilities of the child are developing. Malnourishment and anaemia do not help children to achieve and to learn when they go to school.

Significant also in this list of preventive measures is the immunization of children against the major vaccine—preventable diseases: namely through DPT vaccine (diphtheria-pertussis-tetanus vaccine), and vaccines against polio, measles and TB. Other childhood diseases that have a devastating effect on the health and well-being of the child are diseases linked to diarrhoea. They are among the major causes of stunted growth and may lead to early death among the children of poor communities. Diarrhoea can be avoided by observing sanitary measures in the handling of children's food and by general cleanliness of the child and his/her environment.

### *2. Early detection and treatment of disability*

Research findings in a developing country in Africa (6) have shown that 14 per cent of all disabilities occur before the age of 5 years, and about 53 per cent occur before age 10. During these early years of the child's life, the mother is usually close to the child and therefore the person most aware of any changes in his/her appearance or behaviour. Hence it is important to alert mothers and make them aware of the various symptoms that may be indicative of potential disorders. Such awareness programmes could be incorporated into primary health care (PHC) programmes, mother and child health (MCH) programmes, and antenatal and immunization programmes. If symptoms appear in the child, the mother should promptly seek medical assistance. It has been shown that many disorders can be treated in their early stages. However, if they are left untreated, they may cause permanent impairment.

### *3. Rehabilitation of the disabled*

The disabled child deserves the same opportunity in life as other children of the same age and sex. Such opportunities would help make them productive members of society. Whether disabled children are at home or in specialized centres and institutions, it is usually females who attend to them. Therefore, in the case of a disabled child, it is the mother who is expected to help him/her in the rehabilitation process. Being able to deal with and help a disabled child may require special training, but once more who but the mother would be willing: she should be encouraged to acquire the necessary training. In a case-study of disabled females who succeeded in overcoming the barrier of their respective disabilities, it was clear that family support, particularly the support of the mother, was the key factor and was instrumental in rehabilitating and overcoming the psychological barrier of the disabilities (7).

The first and primary task of the mother of a disabled child in the process of rehabilitation is to acknowledge the disability, but fully realize that it can and should be helped. The mother of the disabled child should realize that the child has potentialities that need to be developed. The child should be encouraged to take care of himself or herself, and should be assigned responsibilities like other children. It has been noted that disabled children who have been spared responsibilities at home have also been denied privileges and rights. The mother should encourage siblings and other family members to share with the disabled child at home in playing games that could enhance and attract his/her attention and concentration, develop thinking and comprehension and help to acquire behavioural patterns.

The mother should involve the disabled child in family activities, such as meeting visitors and relatives. Such involvement makes the disabled child feel that the family is not rejecting him/her. That may encourage in the child the will and desire

to participate with others, and develop a feeling of self-esteem. In addition, the mother should accompany the disabled child to parks, gardens, clubs, and other outdoor activities. She should bring the child into contact with the social reality. All that helps to change a great deal of the child's self-image and increases his/her willingness to integrate in society.

Last but not least, mothers of disabled children should be a source of support and reinforcement to each other. They should act together to be role models in order to bring about change and alleviate the barrier of disability in society.

### C. Discussion and conclusion

It becomes evident from this paper that childhood disability can occur from a multiplicity of causes; some of them are congenital, others are environmental, social or cultural. Consequently, some of these causes are easier to prevent than others. Most of the factors that lead to childhood disability are interrelated and act in a spiral. Though the factors have been presented in this paper independently, the author is fully aware of their interdependence, which makes them tougher to address, but not impossible to correct. Therefore, many of these factors have to be addressed in a comprehensive manner in order to achieve success.

Another factor that needs to be pointed out is that having a disabled child is especially devastating to the mother. It is the mother who is the primary care-giver of a disabled child. In a society where women are generally marginalized, mothers may not be able to go very far towards helping their disabled children. Women need to be empowered to undertake measures that help prevent, or at least minimize, the incidence of disability among children. Women need to be empowered to take rehabilitation measures to improve the status of their disabled children. This can only be achieved by improving women's own status.

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3. A cretin is a dull-looking child, underdeveloped mentally, physically dwarfed, with a large head, thick legs, pug nose, dry skin, scanty hair, swollen eye-lids, short neck, mute, short thick limbs, clumsy, uncoordinated gait (source: Oakes' Pocket Medical Dictionary, 9th ed., Edinburgh: E. & S. Livingstone Ltd., 1961).

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# الأطفال المعوقون
# أسباب الإصابة ودور الأسرة في منعها، والتشخيص المبكر للإصابة، والتأهيل

(ملخص)

اعداد
د. نازك نصير

## مقدمـــة

يعتبر التكاثر من أهم وظائف الأسرة التي تمارس بفخر وذلك لحفظ الجنس البشري - وعلى ذلك يتحمل الوالدان المتاعب بسعادة وترحيب وهي ظاهرة عامة بين البشر.

إلا أنه توجد بعض الحالات لأطفال يولدون في حالة خلقية قد تمنعهم من ممارسة حياتهم كنظرائهم من نفس العمر والجنس، وقد تكتسب هذه الحالة، أي الاعاقة، قبل أو بعد ولادتهم مما يسبب الآلام لوالديهم وأعباء على المجتمع. لذلك فالتشخيص المبكر والتدخل العلاجي وبرامج التأهيل تعتبر عوامل هامة لتحويلهم الى عناصر منتجة في المجتمع.

وهذا البحث يناقش أسباب الاعاقة ودور الأسرة في منع هذه الحالات أو علاجها ثم تأهيلها، مع ملاحظة أنه يهم أساسا دول منطقة الإسكوا.

### أسباب إعاقة الطفل

سأناقش في هذا الفصل، عوامل اعتلال الأطفال التي قد تتسبب في اعاقتهم وسأستخدم تعريفات منظمة الصحة العالمية كالآتي:

الاعتلال: فقدان نفسي أو جسدي أو عضوي في تركيب أي وظيفة.

العجز: انعدام (ناتج عن اعتلال) القدرة على تأدية نشاط بشكل طبيعي أو الحد من هذه القدرة.

التعوق: ضرر يمس فردا معينا - ينتج عن اعتلال أو عجز يحد من تأدية دور طبيعي بحسب عوامل السن والجنس والعوامل الثقافية والاجتماعية أو يحول دون تأدية هذا الدور بالنسبة لذلك الفرد.

ويعتمد اختلاف الحالات التي قد تنشأ قبل الولادة أو اثناءها أو بعدها على أسباب متعددة سأقدمها في مجموعات ثلاث:

(أ) قبل الولادة حيث تبدأ الحالة وقت الاخصاب أو قبل الولادة بسبب عامل أو أكثر، كالآتي:

(١) زواج الأقارب - وهي حالات متفشية في البلاد العربية خاصة بين أبناء العمومة وقد تتجمع عوامل الوراثة لتنتج أطفال عاجزين عقليا أو عضويا؛

(٢) الأطفال ناقصو الوزن - وهم معرضون عادة لحالات القصور العضوي وغالبا ما تكون أمهاتهم إما صغيرات جدا في السن أو متقدمات في السن وقد تنشأ هذه الحالة من الولادات المتكررة على فترات قصيرة ومتتالية؛

(٣) سوء تغذية الأمهات أثناء الحمل - أو نقص بعض العناصر كاليود مثلا مما يؤدي الى مولود متخلف العقل مشوه الجسم.

(ب) أثناء الولادة بعض عمليات الولادة تتم في مناخ غير صحي وقد تؤدي الى تهتك في أنسجة الطفل وبالتالي اصابته بعجز مستديم؛

(ج) بعد الولادة: وهي حالات متعددة وسأوجزها في ٤ مجموعات، كالآتي:

(١) عوامل خاصة بغذاء الطفل: في حالات الرضاعة الطبيعية - تعتمد نوعية وكمية لبن الأم على نوعية غذائها - فإذا كانت الأم تعاني من سوء التغذية، فسيتعرض الطفل لبعض الأمراض كالكساح نتيجة لنقص فيتامين "د" وعدم سلامة النظر نتيجة لنقص فيتامين "أ"؛

(٢) عوامل الفقر: وهي حالة تكاد تكون عامة في الدول النامية -ومنها دول المنطقة- من سوء تغذية الأم والطفل وتلوث البيئة (الماء والصرف الصحي) وما ينتج عنها من أمراض كالاسهال الذي يؤدي الى قصور في النمو. وقد لوحظ أن تكرار هذه الأمراض يهدد الطفل بفقدان الشهية وقلة امتصاص الطعام أو عدم الاستفادة منه نتيجة التقيؤ والاسهال؛

وبسبب الفقر قد يستخدم الأطفال للعمل في المنزل وأماكن العمل مما يحرمهم من التعليم ويقودهم الى الأمية - والأمية والاعاقة عاملان متلازمان، فالأمي يجهل الطريق لتحسين حالته اقتصاديا ونفسيا واجتماعيا - وغالبا ما يتحول المعوق إلى أمي غير قادر على الاستفادة من برامج التأهيل؛

(٣) الحوادث: ان انشغال الأمهات واهمالهم للطفل قد يؤدي الى حوادث على الطرق أو في المنزل أو في العمل - وما يتبع ذلك من بتر

للأطراف وغير ذلك، خاصة في البلاد النامية، حيث أن الطرق غير مهيأة للأعداد الكبيرة من وسائل النقل التي غالبا ما تنقصها وسائل السلامة فيكون الأطفال أكثر الضحايا. هذا بالاضافة الى أن عمل الأطفال في المصانع قبل إكتمال تدريبهم على الماكينات يؤدي لكثرة اصاباتهم؛

(٤) الحروب: ان الإصابات وخاصة في الحروب الحديثة تنتشر بين الجميع كباراً وصغاراً، رجالا ونساء ما يترك الكثيرين مشوهين أو معوقين.

دور الأسرة في التعايش مع الطفل المعوق

غالبا ما تكون الأم هي المسؤولة الأولى عن رعاية المعوق في الأسرة ولذلك فإن دورها هام جدا في منع الاصابة أو التعامل معها ومتابعة تأهيل المعوق.

(أ) منع الاصابة: ان فحص الراغبين في الزواج وخاصة الأقارب عامل مهم لتقليل حالات الاعاقة. وقد أثبتت الأبحاث الحديثة أهمية وضع الأطفال حديثي الولادة على نظام غذائي خاص مع التشخيص المبكر للحالات، وكذلك مراعاة تغذية الأم بوجبات غنية بالفيتامينات والبروتينات والحديد أثناء الحمل والرضاعة وادخال اضافات من الطعام الصحي تدريجيا على وجبات الطفل.

كذلك فإن تطعيم الأطفال في المواعيد المقررة واتباعها بدقة يمنع الكثير من الأمراض وخاصة منها شلل الأطفال؛

(ب) التشخيص المبكر وعلاج الاعاقة - أثبتت الابحاث أن حوالي ١٤ في المائة من حالات الاعاقة في البلدان الأفريقية النامية تحدث قبل سن ٥ سنوات وأن ٥٣ في المائة تحدث قبل سن ١٠ سنوات، وغالبا ما تكون الأم ملاصقة للطفل في هذه السن فيسهل عليها ملاحظة أي تغييرات ظاهرية أو سلوكية للطفل. ولذلك فإن تثقيف الأمهات ومساعدتهن طبيا عامل هام في علاج هذه الحالات مبكرا في حين أن اهمالها قد يتسبب في عاهات مستديمة؛

(ج) تأهيل المعوقين - ان تأهيل المعوقين سواء في منازلهم أو في المراكز المتخصصة يعطيهم الفرصة ليكونوا أعضاء منتجين في المجتمع - لذلك فإن تأهيل الأم وتشجيعها على التدريب على هذا العمل يعتبر عنصرا أساسيا خاصة إذا اقتنعت بامكانية العلاج وبأن طفلها لديه قدرات يمكن تنميتها، مما يشجع الطفل على تحمل بعض المسؤوليات كأقرانه ومشاركة أفراد الأسرة يمكن تنمية قدراته الذهنية والعضوية وخاصة المشاركة في النشاط الاجتماعي للأسرة واصطحابة في النزهات الخارجية لبعث الثقة في نفسه للتفاعل وبث الرغبة لديه في الاندماج في المجتمع الخارجي. كما يجب أن تتعاون أمهات المعاقين بتبادل الخبرات فيما بينهن وتشجيع بعضهن البعض ليقمن سويا بتغيير نظرة المجتمع للمعاقين.

ويتضح من هذه الدراسة أن الاعاقة في الطفولة قد تحدث لأسباب متعددة بعضها وراثي والبعض الآخر بيئي أو اجتماعي أو ثقافي، وبالتالي فقد يسهل منع الإعاقة احيانا أو يصعب منعها في أحيان أخرى. ونظرا إلى أن أغلب العوامل المؤدية للاعاقة متشابكة، فإنه يجب مواجتها باسلوب متكامل حتى نصل لنتائج ايجابية كما ان وجود طفل معوق في الأسرة يحطم معنويات الأم خاصة في المجتمعات التي لا تتمتع فيها المرأة بوضع مؤثر - ولذا فإن اعطاء المرأة بعض السلطات يسهِّل من مهمتها في منع أو تقليل حالات الاعاقة بين الأطفال وكذلك مساعدتهم على التأهيل.

# WOMEN AND DISABILITY: THE ROLE OF THE FAMILY

*Madiha El Safty*

## I. DISABLED PERSONS: PRESENT SITUATION

A study of disability in societies of the ESCWA region, as in societies of developing countries in other regions, faces a number of problems, some of which are rooted in the culture; others reflect the situation in the formal system. In the first place, statistics on disability are scant, and in most cases unavailable. Underlying this deficiency are predominant cultural values that consider disability a stigma not to be exposed, but rather to be veiled in secrecy. Consequently, disability is underregistered. In addition, a lack of awareness of the rehabilitation of disabled persons increases the disregard for this segment of the population. The prevalent belief is that once disabled, always disabled. Society does not provide sufficient services for disabled persons. Services offered by the State cover only a small fraction of this segment. Non-governmental organizations (NGOs), in most cases, complement this deficiency, but in a limited way. The overall provision of services for disabled persons in the countries of the region does not in any way ensure total coverage. Tables 1, 2 and 3 reflect this situation, revealing the insufficiency of rehabilitation services for disabled persons: they are based on ESCWA data. It must be noted that in some cases of disability NGO services exceed those provided by the Government, as apparent in table 1, with Iraq and the Syrian Arab Republic being examples where only governmental facilities for disabled persons are found. Egypt has a relatively high number of facilities, as shown in table 1, with those run by the NGOs considerably exceeding Government facilities. The general distribution of the services for handicapped persons as shown in the tables is, however, not only limited and deficient, but also as such reflects the situation in the region. It is clear that there is a shortage of care facilities as well as insufficient information.

A relevant factor in this respect is that in most cases statistics cover education, rehabilitation, and/or medical care. However, the majority of handicapped persons do not seek such services and therefore go unnoticed by the official data and thus are unregistered.

One other problem that appears with respect to disabled persons in this region is the definition of disability. The term does not cover a uniform population. Neither is it a standard concept. There is a variation in the definition of disability, between mental and physical, as well as a variation in the degree of disability, ranging between partial and total. Many a partially disabled individual can go throughout his/her life as "normal", with all the possible consequences, both positive and negative, that such a situation might entail. It is the absence of a clear definition of the term disabled

persons that may be partially responsible for the underregistration of disabled persons, especially in a population which lacks awareness of the condition. It is even common among some traditional segments of society, especially in rural areas, to view disabled individuals as holy persons enveloped in sanctity and endowed with supernatural powers. This sanctity is highly exaggerated. People from the community seek special blessings from these disabled individuals in cases of illness, trouble, crises, and/or disasters. These disabled persons are usually showered with gifts, especially when their disability denies them the satisfaction of enjoying worldly pleasures, in which case the community places them in the position of a divinity, surpassing even sainthood. Their disability is seen by simple people as a special endowment from God, a hardship which highlights their supernatural power of tolerance. It is common that upon the death of such "saints", a shrine is built in their place of residence to commemorate their saintly services to people. Many a shrine in the villages of the Arab world includes the body of a disabled person whose handicap gave them holy attributes in the eyes of the community.

At the State level, policies related to disability in the countries of the ESCWA region are highly fragmented: they lack a cohesive form. Government laws for handicapped persons are scattered between the sectors of labour, social security and education. Attempts have been made by some countries, such as Egypt, to combine these laws in one code that serves the interest of disabled persons, but the general situation of the region still remains one in which a number of regulations/policies related to disabled persons are included among other State concerns and not as separate policy.

Furthermore, in the ESCWA region the neglect of disabled persons as a segment of the population is apparent in the obvious shortage of personnel qualified in this area. Very few, if any, training programmes are given to provide the manpower for working with disabled persons, whether in education or rehabilitation. The educational systems in the countries do not include such programmes. In the absence of qualified providers of service to handicapped persons, their chances are extremely limited.

This paper is an attempt to review the situation of disabled women in a clearly male-dominated society, with special emphasis on the role of the family, not only *vis-à-vis* the disabled family member but more as an agent in disability.

## II. DISABLED WOMEN: A DOUBLE DISADVANTAGE

It is an undeniable fact that women in the countries of the ESCWA region still suffer from problems of inequality/discrimination, in spite of the many rights they have

gained in most of these societies in their pursuit of emancipation. Disability in a woman further aggravates this situation. She is therefore doubly disadvantaged.

A review of the situation of disabled women cannot be made without taking into account the broader context of their ascribed status. It must not exclude gender considerations. In a society where females come last in health care, nutrition and education, the chances of a disabled woman are minimum. The stigma of disability is further doubled. In this case, education/rehabilitation may be denied by the family for fear of publicly exposing their tragedy. What aggravates the situation is that the disabled woman loses her right to marriage and motherhood in a culture which not only places a high value on these but also considers them the basis of a woman's identity. Other members of the family, especially females, are affected by this handicap, and their chances for marriage are greatly reduced. It is not the fear of the hereditary influence of the disability that decreases the marriage possibilities for the other females in the family of a handicapped individual as much as the stigma of the disability itself, or rather the shame associated with it.

A disabled woman as such is not only an emotional burden to the family but a loss to productivity as well, with the resulting negative consequences on society at large, since the proportion of disabled women in the labour force is low in all countries of the region. These women are not granted equal opportunities of employment: rather, their chances in this respect are highly limited. The underprivileged segments of handicapped women cannot be disregarded in the endeavours to raise female productivity. If they are denied education/rehabilitation, as is commonly the case, they are an economic burden, a fact which doubly aggravates the situation of low female productivity in the region.

Since female life expectancy is universally longer, disability rates among the elderly increase, which is even more of a problem in the Arab world in the absence of total health coverage. Especially in this age group, problems of physical impairment appear, such as blindness and deafness, which require technical aids not easily available because of inadequate medical services. Additional problems are posed by the low level of technologies in most cases and the high cost of such technical aids.

## III. WOMEN AND DISABILITY: DIMENSIONS OF THE RELATION

The relation of females to disability has dimensions other than its direct effect. In the first place, women can be responsible for the disability of other members of their family, especially offspring. In the second place, they are in most cases the care-givers of disabled kin.

The responsibility of women for disability of family members is related to a number of variables. In societies where women are highly disadvantaged with respect

to receiving health services, pre-, peri- and postnatal care are of little, if any, concern. The causes of impairment may be attributed to conditions during pregnancy and/or childbirth. Just as the lack of adequate medical care for mothers during these two periods is a major cause of the prevalence of impairment among children, medical supervision of mothers is an important step in the prevention of impairment. In most cases, because females are the last to receive health care, many a woman can go through her pregnancy with untreated diseases or health problems that are totally undetected; hence she receives no treatment. Such cases are reflected in disabled offspring. In addition, the poor nutritional conditions of women in general cannot be underestimated as a significant variable negatively affecting the pregnant woman and child. Viral infections may occur during pregnancy; they can be dismissed as minor and go untreated, with the pregnant woman not realizing the possible complications for the foetus. Traditional cultures usually have special treatments for health problems. However, the probability of certain drugs, herbs and/or curative measures having a negative effect on pregnant women cannot be disregarded.

The more advanced techniques of premarital medical examinations are not yet common in the countries of the region, but ideally they can, if made available and acceptable, prevent many possible impairments among babies, especially as data reveal that 20 per cent of the causes of disability are congenital in nature.[3] The health situation of women in the region does not guarantee safe motherhood.

Trauma during childhood may also result in a disabled baby. Deliveries by midwives are prevalent. The traditional midwife is still a popular health practitioner in some countries of the ESCWA region, especially among traditional segments of society, in particular rural and Bedouin areas. The delivery of a child by someone without professional training can result in a number of complications for both mother and child, some of which have permanent, long-lasting effects.

In the above two situations—namely, disability that may result from undetected health problems, especially during pregnancy, and/or complications during childbirth—female illiteracy looms as a strong relevant variable. An illiterate woman lacks awareness of health concerns, including medical care during pregnancy. In addition, when seeking health services, she prefers a traditional practitioner with all the problems and complications that could result. A third factor of equal—if not greater—significance in this respect is the high fertility correlated with illiteracy among females. Frequent pregnancies without proper spacing between children are another cause of disability among offspring. The woman without education defines her identity through her fertility—in fact, she has no other criterion in her self-perception as a

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[3] M.A.S. El-Banna, "The situation of the disabled in Egypt", Proceedings of the Conference on the Capabilities and Needs of Disabled Persons in the ESCWA Region, held in Amman in November 1989 (E/ESCWA/SD/1992).

female. She is likewise highly threatened by the loss of fertility, and she consequently clings to it for her security. The result is unceasing pregnancies through her reproductive period and the high probability of "impaired" babies. Relevant in this respect is pregnancy at a very young age and an old one—two situations which are common among women in the countries of the ESCWA region, and which raise the fertility rate compared with other countries. ESCWA studies have shown the high incidence of impairment among children born too early or too late in a woman's reproductive period.

The strong correlation between female illiteracy and disability in a family is not limited to matters of fertility and reproduction. It extends to different aspects of family life. Improper care of family members, especially children; negligence; ignorance of basic safety measures; lack of concern for nutrition; exposure of children to street and other hazards—all such factors are closely related to female illiteracy. Education for women is the triggering factor for awareness not only in matters of health, but in all other aspects of life, not excluding proper socialization of children and proper care of all family members.

Poverty also appears as a factor of strong correlation to disability, and is reflected in the high incidence of disabilities in rural areas in particular. Poverty is related to improper health care, malnutrition and illiteracy—all of which are crucial variables in disability. Furthermore, in a family where there is a disabled member, it is usually the woman who acts as care-giver. Since it is the traditional role of the woman to be in charge of the household, disabled persons fall under this domestic sphere, with all the chores such responsibility entails. Here again one sees the importance of education for the woman care-giver and the possible dangers if she is illiterate. However, the increasing education and employment for women in the ESCWA region, in line with the transformation in society, raise the issue of the participation of other family members in caring for disabled persons.

## IV. THE ROLE OF THE FAMILY

The family in the countries of the ESCWA region is still characterized by strong close ties between its members, in comparison with families in some other parts of the world; this is in spite of the transformation the family has been undergoing. Its major social functions remain intact.

The need for cohesive relations within a family becomes doubly important when it includes a disabled member, let alone one from the female sex with its underprivileged, disadvantaged status. The role played by the family in such cases is reviewed in the following points and recommendations:

### A. THE STIGMA OF DISABILITY

The disability of the female should never be considered a stigma by her family; neither should it be seen as a shameful condition to be veiled in secrecy. The attitude of the family should be characterized basically by a position of acceptance of the fact, sad and depressing as it may be for some or all of its members. The person who is dealing with the handicapped family member should not give way to negative feelings; this not only reflects the inner feelings of this individual, but also leaves a negative impact on the disabled family member, whose emotions are already affected and who is therefore highly vulnerable.

### B. NEGLIGENCE

In line with the effort to disguise a handicapped female in the family is the resulting attitude of negligence. There is a common feeling that, pathetically enough, the handicapped female does not deserve to live. She is the last in the family to receive care and domestic services, let alone special attention. Such attitudes must be overcome. The media can play a role in this respect. Egyptian television has been concerned about disabled persons and has recently been providing special programmes with the objective of developing awareness among the public of the care of disabled persons as well as orienting families of disabled persons towards institutions for the rehabilitation of different kinds of disabilities, both physical and mental. A number of successful handicapped individuals are even shown on television, and the stories of their miraculous success are told, in the hope of setting examples for others with the same or similar conditions.

The exposure of the work done by rehabilitation centres in the media is of great importance, because of the prevailing tendency among families to deny their handicapped female members such services as part of the general attitude of neglect towards them.

The family should therefore guarantee the disabled female proper care not only within the family circle but, if need be, from rehabilitation centres. However, emphasis should be placed on the obligation of the family to provide the required rehabilitation at an institution or centre without detaching itself totally from the disabled family member seeking the service. Rehabilitation should take place in collaboration with the family in order to avoid any possible resulting psychological or emotional problem if the disabled member is isolated from her family; this psychological and emotional isolation can be very detrimental to her well-being.

### C. OVERINDULGENCE

At the other extreme, the other family members should not be overindulgent towards the disabled member. It is their duty to teach her to adjust to her surrounding

environment with as much "normality" as her handicap allows. Overindulgence increases a disabled family member's dependence and does not help her condition, especially in those cases where the disability is not severe and where intervention through rehabilitation measures can make a difference or can allow the disabled person to achieve a certain degree of independence in handling her own affairs—at least, some simple daily tasks.

### D. GUILT FEELINGS

In many families with disabled individuals, there prevails a sense of guilt, especially among the parents, and in particular when they have other "normal" offspring. This situation can be very obvious in cases when the family includes more than one daughter, one of whom is disabled. The others live a normal life, assuming that the stigma associated with their handicapped sister does not ruin their chances of marriage. The discrepancy in the life chances of the sisters cannot be underestimated as a triggering factor for feelings of guilt in the parents. It is necessary that they work hard not to let their attitude towards their daughters reflect such feelings, since the consequences can be negative for everyone. It is expected that the sisters themselves already suffer from these feelings of guilt, and the parents' role is important in helping them cope with the situation to avoid any disruption in family relations.

The same guilt feelings can be found among siblings of the opposite sex—namely brothers in the case of a handicapped sister. However, the sense of guilt is more strongly felt among siblings of the same sex, because of the apparent difference in lifestyles, with the disabled girl greatly disadvantaged.

### E. LIMITED ABILITY

The family should understand the limits of the ability of the handicapped family member, and not be overdemanding. They must not raise their expectations for her performance, in whatever aspect. It is common for the parents of mentally retarded children in particular to push them hard towards scholastic performance, for which their limited mental ability does not qualify them. The resulting situation is one of frustration for both sides. The inability of the parents to face the child's disability makes them unwilling to accept it and consequently they strain his/her mental power. Many schools include such cases among their students. These children have to suffer one failure after another, whereas if they were directed towards vocational training suited to their abilities they would achieve better results.

Training the mentally retarded includes a number of vocations in which they have a chance to excel, such as carpet weaving, carpet laying, and knitting. It is in this direction that the family should orient these cases and in this way avoid the feelings of frustration that both they and the disabled family member suffer. At the same time vocational training can help to overcome the handicap. The disabled family

member will have learned a vocation and will have been provided with a good source of income.

### F. PREVENTION OF DISABILITY

Needless to say, the role of the family starts at the preventive stage. It is crucial that a pregnant woman be provided with proper medical care throughout her pregnancy. Regular examinations under the supervision of a physician are required. Strict adherence to medical instructions must be the norm, and no drug or curative measure should be taken by the woman without consulting her doctor. A woman should have a general check-up at the onset of pregnancy, but with the current lack of awareness of female health concerns, this is rarely the case. Prenatal care is not assured. Even simple infections must not be dismissed. Nutrition for the pregnant woman must be top priority in the family. The "normal" prevalent situation of the woman being last in nutritional priorities must be reconsidered. She should come first, at least during her pregnancy. Safe motherhood is thus a crucial aspect in preventive measures.

Furthermore, deliveries must be performed by professionals—a doctor or trained nurse, to avoid any possible trauma or complications for the child. A prevailing Arab tradition highly values consanguineous marriages. Such relationships are responsible for a significant proportion of disabilities. Reports estimate that 67.5 per cent of the parents of the mentally retarded children in Jordan are related (E/ESCWA/SD/1995/1). This tradition is especially common in rural and Bedouin areas: in fact, it still is the preferred type of marriage. It therefore becomes necessary to discourage marriages between relatives in order to help reduce the incidence.

The preventive role of the family should guarantee early detection of an impairment, if one is found. Early detection should guarantee early treatment to minimize the incidence of disability and control it at an early stage, if possible. This requires awareness as to impairment/disability, even in its mildest form. The ambiguity of the definition of disability needs to be clarified in order to ensure early detection and thus also early treatment.

Prevention of impairment by the family requires a cautious, caring and alert attitude on the part of the parents, especially mothers, with respect to exposure to hazards, whether at home or on the street. Careful parents protect their children from disability. No child should be left unattended, nor should poisonous material or sharp instruments be left around the house within the reach of the child.

One aspect of the preventive role of the family has been increasing in many countries of the region. This is in the area of immunization, vaccination against diseases that may result in any form of impairments such as poliomyelitis and meningitis, which have become widespread in the region, and extensive campaigns by

the media support vaccination programmes. However, not all societies in the region respond to the serious efforts for widespread immunization. Rural areas in particular are still not totally covered. In general, however, the spread of immunization has reduced the incidence of possible impairments resulting from diseases.

The responsibility of the family in preventing disability extends even beyond the home and close community boundaries. Families that allow their offspring to engage in hazardous work are guilty of exposing them to the high probability of impairment. The work environment is responsible for a significant proportion of impairments. Child labour as a social problem is a relevant variable in the incidence of accidents.

In a general sense, appropriate prevention by the family can play a major role *vis-à-vis* disability. If properly done, it can reduce the occurrence of disability.

### G. EMOTIONAL/PSYCHOLOGICAL SUPPORT

Although all of the preceding aspects of the role of the family are crucial with respect to the care of disabled persons, the most important responsibility relates to the need for support, which is essential for handicapped persons. The vital factor to their existence, survival and perseverance is the emotional, psychological and moral support that can best be provided by the family and without which very little can be achieved. A sheltering, caring and nurturing environment is what they need.

## V. A FINAL WORD

This paper has tried to review the situation of disabled women in the ESCWA region, with special emphasis on the role of the family in caring for them, not excluding the relation of women to disability in general. In a culture where disability is a stigma, where consequently awareness of the care of disabled persons is lacking, where the provision of services for their rehabilitation is deficient, where a well-defined policy for disabled persons is absent, and where data about them are scant, women face a compound disadvantage. This is where the role of the family takes on great significance, since it is the milieu that can best give disabled persons the support they need, especially since the family in the region still holds its members together in a close network of relations. Awareness of rehabilitation starts with the family.

The fact remains, however, that rehabilitation services for disabled persons outside the family cover only a small segment of the handicapped population. In many cases, non-governmental organizations (NGOs) have been successful in this respect. Mention should be made of the world-famous "Light and Hope" society for blind girls in Egypt. This NGO has provided a very good channel for rehabilitation. A well-organized orchestra of high standard has been touring the world, demonstrating to the

international community the developed inherent talents of the blind girls who are members of the orchestra. By recruiting members of the orchestra from this disabled segment of society, society has helped them overcome their handicap and succeed in their attempt to become active members of the community. The NGO could not have performed this service—in addition to many others that it provides—without the first step, which was taken by the families of these girls who realized that their daughters could receive the help they needed from this institution.

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# المرأة المعوقة ودور الأسرة

(ملخص)

إعداد
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يعكس الوضع الراهن للإعاقة بدول اللجنة الاقتصادية والاجتماعية لغربي آسيا (الإسكوا) بعض المشكلات، أولها ندرة البيانات المتاحة عن الظاهرة، والتي تعكس غياب الوعي بها وبالتالي عدم تسجيلها بشكل رسمي. كما أن الخدمات التي توفرها حكومات هذه الدول لا تغطي هذه الشريحة بشكل كاف، بل إنها تعتبر في مجملها قاصرة. ولذلك تقوم المنظمات الأهلية في هذه المجتمعات بتغطية هذا القصور. وإن بقي الوضع العام يعكس نقصاً في هذا العدد.

ومما يضيف إلى المشكلات القائمة هو غياب تعريف موحّد لمفهوم الإعاقة، فهي قد تكون جسدية أو ذهنية، كما انها تتراوح بين الإعاقة الجزئية الشاملة. بل إنه في بعض المجتمعات التقليدية وبالذات الريفية منها تبرز ظاهرة خاصة تحيط المعاقين بهالة من القدسية تضعهم في مصاف أولياء الله الصالحين والذين يتمتعون بقدرات خارقة وبركات غير عادية. وبالتالي تبنى لهم الأضرحة عند الموت وتصبح مزاراً لجموع غفيرة فيما بعد.

وتفتقد دول الإسكوا إلى سياسة موحدة خاصة بالمعوقين بل إن السياسات الخاصة بهذه الشريحة تتواجد بصورة مجزأة وتتناثر بين السياسات الأخرى دون تنسيق بينها.

وبالإضافة الى ذلك فإن غياب المتخصصين المدرّبين على التعامل مع المعوقين يمثل مشكلة لها أهميتها في هذه المنطقة، وفي ظل هذا القصور تتفاقم المشكلات المتعلقة بتوفير الخدمات لهم.

وتتعرض هذه الدراسة لفئة من بين شريحة المعوقين وهي فئة النساء واللاتي تصبح مشكلة الإعاقة لديهن مشكلة مضاعفة بسبب وضعهن في جنس يعاني من تفرقة واضحة فيما يتمتعن به من حقوق وبالتالي تصبح وصمة الإعاقة لديهن ذات أبعاد كثيرة تتمثل في حرمانهن من الحق في حياة سليمة. إذ تقل فرصهن في الزواج والإنجاب بل وفي التعليم والعمل أيضا. ولا شك أن مثل هذا الوضع له تأثيره على عملية الانتاج في المجتمع متى تقلص دور المرأة فيها.

ويجدر الذكر أن أهمية التعرض للإعاقة لدى النساء تزداد لارتفاع نسبة المسنات منهن وذلك بسبب زيادة عدد النساء بين شريحة المسنين بشكل عام بالإضافة الى عدم توفر الأجهزة التعويضية التي بوسعها أن تعينهن في هذه السن وأيضا ارتفاع أسعارها بالنسبة لمعظمهن.

وتعتبر علاقة المرأة بالإعاقة ذات أكثر من بُعد. فهي قد تكون مسؤولة عنها وذلك عندما تهمل في الحصول على الرعاية الصحية بشكل عام وخاصة أثناء الحمل والإنجاب وما يمكن أن يترتب على ذلك من إعاقة في الجنين، خاصة وأن النساء كثيرا ما يلجأن الى الطب الشعبي وبالذات الدايات دون اللجوء الى الرعاية الصحية السليمة. وتبرز أهمية التعليم لدى النساء في هذا الصدد حيث يؤدي انتشار الأمية بينهن الى إهمال صحة المرأة وعدم الوعي بالأضرار التي يمكن أن تصيبها أو تصيب الجنين في هذه الحالة. كما أن ارتفاع نسبة الخصوبة بين النساء الأميات يشكل خطرا آخر، فقد أثبتت الدراسات زيادة نسبة الإعاقة في المواليد بين الأمهات ذوات الخصوبة المرتفعة وأيضا بين الأمهات صغيرات السن ومن ينجبن في سن متأخرة.

ويأتي الفقر كأحد المتغيرات الهامة في الإعاقة ويبدو ذلك في ارتفاع نسبتها في الريف حيث يتفشى الفقر.

أما البعد الآخر للعلاقة بين النساء والإعاقة فيتضح في أنهن في معظم الحالات مسؤولات عن رعاية المعوقين من أفراد الأسرة. وهنا يبرز سؤال يتعلق بالوضع الناتج عن عمل المرأة وانشغالها عن هذا الدور الهام وضرورة مشاركة بقية أفراد الأسرة في هذه المسؤولية مع التحول الذي يمر به المجتمع.

وفي الواقع فإن للأسرة في منطقة الإسكوا دوراً عظيماً في رعاية المرأة المعوقة وخاصة ان الأسرة في هذه المجتمعات مازالت تحتفظ بتماسكها ولم تتفكك بالمقارنة مع الأسرة في بعض المجتمعات الأخرى وبالتالي يصبح لزاماً عليها أن تقوم بمسؤوليتها في هذا الصدد من خلال عدة جوانب.

أولاً، العمل على التخلص من وصمة الإعاقة التي تلحق بالأنثى وأن تتعامل معها على أنها فرد منها وليس عاراً يُحاط بالسرية.

ثانياً، عدم إهمال الأنثى المعاقة، بل إعطاؤها الرعاية اللازمة لها من خلال مراكز تأهيل إذا احتاج الأمر مع الإبقاء على العلاقة الأسرية وعدم فصم عُرى هذه الرابطة.

ثالثاً، عدم المغالاة في تدليل المرأة التي تعاني من إعاقة حتى لا تعتاد أن تكون عالة على غيرها بل لا بد من مساعدتها على محاولة أن تعيش حياة طبيعية في حدود ما تسمح به عاهتها.

رابعاً، محاولة التخلص من الشعور بالذنب الذي عادة ما يخالج أسرة المعوق أولاً لإحساس أفرادها بالفارق بينهم وبين الفرد المعوق وثم لاحتمال وجود مسؤولية من أحدهم نحو سبب الإعاقة.

خامساً، ضرورة تعامل الأسرة مع الأنثى المعاقة في حدود قدراتها سواء كانت الجسمانية أو الذهنية، دون مطالبتها بما هو فوق طاقتها.

أما الدور الأهم للأسرة فهو الوقاية من الإعاقة ومنع حدوثها أصلاً وذلك بتوفير الرعاية الصحية للأم وضمان الأمومة الآمنة. كما أن من واجب الأسرة حماية أفرادها من الحوادث سواء المنزلية أو غيرها وتأتي عمالة الأطفال في ذلك الإطار إذ تمثل مجالاً واسعاً للحوادث التي قد تؤدي إلى الإعاقة.

ولا تحول كل الأدوار السابقة في مجال الإعاقة للأسرة من توفير المساندة النفسية والمعنوية للأنثى المعاقة حتى تستطيع أن تعيش حياتها بأقل قدر من المعاناة.

وتنتهي الدراسة بالإشارة الى تجربة ناجحة لتأهيل الإناث المعوقات تتضح في جمعية النور والأمل المصرية التي استطاعت بجهود أفرادها ان تخلق فرقة موسيقية ذاع صيتها دولياً وأصبحت تجوب أنحاء العالم لتعرض على الدول المختلفة ما نجحت في تنميته من مواهب عظيمة لفتيات كفيفات.