

## 8 Roles of Disabled Children's Parents' Associations

*"One day a friend asked me to meet a woman who had delivered a severely mentally retarded child in order to advise her from my experience with my son ... When we met I told her don't despair, tomorrow will be better and better ... After listening to me the woman said "you just say that because you found who trained you and trained your son for you outside (meaning in the West) but here in Egypt how can I find such opportunity ... You were able to place him in a special school outside, but I have limited means which don't allow me to do so." ..It was then that I told her" but I will help you".... After she left, I kept hearing over and over again her words ... and felt how insignificant my assurance and offer for help was, ...The educational process my son and I went through was long and continuous and required technical skills and resources. ... It was this meeting that gave birth to the idea that we parents of disabled children have to get together and establish an association like those in the western countries, .. we should not wait for government help but we should struggle by ourselves like parents in the west, and establish a school built on the same methods in education and rehabilitation as they have in the west." (Shaker, 1995)<sup>4</sup>.*

### 8-1 Introduction

The previous account given by Ms. Shaker - a mother of a mentally retarded child and one of the main founders of the Right to Live Society, the first Parents association established in Egypt in 1981 - gives a picture of the characteristics of the majority of parents organization established in Egypt to date.

Known to this research to date the number of formally established organizations are 5 to 6 and at least another 4 organizations are undergoing attempts at formation and registration (Shukrallah, personal inquiries, 1996). The formally established organizations were all registered with the MOSA under the law 32. A fact which has delayed the actual establishment of these organizations for some time and continues to hinder others due to bureaucratic procedures laid out by this law<sup>5</sup>.

The majority of these organizations as the account shows us and as will be seen later, represent initiatives of well-to-do parents of mentally retarded children who try to fill the obvious gap in existing governmental and non-governmental services, particularly in the fields of mental retardation and multiply-disabled children. In many instances there was a history of influence of some of these parents from the western special educational schools.<sup>6</sup>

Following is a list of these organizations, their objectives and fields of activities and the different disabilities they cater for. The list is followed by an analysis of these organizations, what phenomena they represent and what the perspective of this development is.

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<sup>4</sup> Translated: Alaa Shukrallah

<sup>5</sup> Among the major complaints that hindered and continues to hinder the establishment of such organisations have been the bureaucratic procedures under the above mentioned law regarding the establishment of NGOs. The Law states that among the prerequisites to registration with the MOSA is the acquisition of a place, a condition which is quite difficult to achieve, particularly in the capital, without securing funding in the first place. However, securing funding or donations requires first to be registered as an NGO. It was against this article that several initiatives among which the above mentioned and the undergoing ones were delayed for some years to be established, while others were totally frustrated and failed to take off.

<sup>6</sup> the stories given by some of these parents there was a history of having placed their children in western countries after discovery of the disability and after obvious frustration with existing attitudes and services in Egypt. Upon returning for various reasons deciding to return and establish such centres as they saw outside.

## **8-2 List of organization of parents of disabled children in order of their date of establishment:**

### **8-2-1 Formally established Organizations**

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#### **Right to Live Society**

Date of establishment	1981
Type of disability	Mental Retardation.
Objectives and fields of activity	Education classes for MR. children from ages 4-16. Vocational rehabilitation for adolescents for ages 16-19 years. Production workshops for MR. from ages 18 onwards. A centre for training of special educational teachers in the area of MR. (established in cooperation with Oslo University, Norway).

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#### **The Bright Future Association**

Date of establishment	1985
Type of disability	Mental Retardation
Objectives and fields of activity	Education classes for MR. ages 8-12 Centre for Vocational Rehabilitation, 12-20 years. Awareness raising and guidance to parents of mentally retarded children

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#### **The Friends of a Bright Tomorrow Association**

Date of establishment	1985
Type of disability	MR. and Multiple Disabilities
Objectives and fields of activity	Establishment of a comprehensive centre including residential care for MR. and Multiply Disabled children. To network to assist disabled to acquire jobs. To provide recreational activities for disabled children.

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#### **Parents and Sons**

Date of Establishment	1991
Type of disability	Mental Retardation
Objectives and fields of activity	To help develop strong public opinion and political lobbying To secure funding of public supported social rehabilitation services for mental retardation and professional guidance for families Build demonstrative models of integrated programs involving educational, vocational rehabilitation and health care Help secure job opportunities and sound work conditions Secure continuous social care for those who are seriously retarded and cannot lead an independent life Develop legislation to protect the rights of disabled

Strengthen prevention through dissemination of information  
Organize training programmes for professional workers to  
improve services

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### **Early Intervention Organization**

Date of establishment	1995-96
Types of disabilities	MR. & Multiple Handicap
Objectives and fields of activity	Provision of early intervention programmes for children Train parents on early intervention Develop appropriate tools and equipment suitable for training and aiding disabled children

In addition to the above, there are at least another six organizations in the process of formation and/or registration. As the organizations have not yet been formed and their charters have not yet been declared, their actual titles are not yet known neither are their detailed objectives and activities.

### **8-2-2 Organizations in the Process of registration**

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#### **1. Organization for Cerebral Palsy Children**

In the process of registration, possibly 1997.

The idea of the organization was developed in 1993 after a national workshop on CP was held by the Palestinian Red Crescent Society (PRCS). However, the parents were met with the bureaucratic constraints mentioned before for registrations. Finally, they have been able to acquire a room in the

#### **Objectives and activities**

**Not declared but according to those developed during the workshop, they included** provision of appropriate services for CP Children

Assist their parents and train them

Advocacy on behalf of their needs.

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#### **2. Autistic**

**An organization is in the planning.**

**The nucleus is again from relatively wealthy and professional background parents and includes several western parents and parents with western education and experience background**

**Established in the face of the clear vacancy of any appropriate services in the field of Autistic Children.**

**It is mostly service-provision-oriented.**

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#### **3. Visually impaired**

**An idea in the planning.**

**It is motivated by the same type of parents as the above.**

**Fields of interest again include appropriate service provision as well as advocacy.**

### **8-2-3 Potential organizations of disabled children's parents in the making, yet representing different background and approach**

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#### **1. Parents support groups (Ain-Helwan & ElNahda) (AHED)**

These two parent support groups are being developed as a goal and an outcome of CBR projects in these areas.

Poor parents of disabled children were encouraged to regularly meet on a weekly basis, learn from each other's experience and work together for the interest of their children and to secure their rights.

The final aim is to develop organizations of disabled parents on the community level representing the needs and aspirations of poorer parents and as a process of empowering them.

Obviously the background of the parents is very different from the above groups. They belong to poorer and very marginalised groups of the society. Their relationship is on the community level.

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#### **Parents Support Groups (SETI, CBR projects)**

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The projects were likewise developed in three projects sites. They cater only for parents of mentally retarded children. Their final objectives are the same as the above.

### **8-3 Discussion and Conclusion**

From the above we can discern the following:

- The majority of organizations are formed from parents of MR. children. This is followed by multiply handicapped particularly CP and then Autistic children. This is probably due to both the presence of negative attitudes particular to these groups on the one hand, concomitant with the obvious deficiency in available services on the other.
- The phenomenon belongs mainly to the eighties and nineties; i.e. very recent. It was originally obviously helped by the experience of the western countries and the international decade of the disabled in which many international donors were willing to assist such endeavors.
- The main trend belongs to parents from highly educated, rich backgrounds with previous knowledge of the western experience. These organizations operate on a national level rather than on the grass-root level. Most of these organizations came as a response to the need for service provision and hence are very service-oriented and related to the needs of their children. Although advocacy is there as an objective, in the main it acquires a secondary position. Among the major needs that was voiced by many of the founders of these organizations have been to secure the future of their children who will not be able to live independently. The usual question asked by parents is "what will happen after we die?" . Different types of residential care plans are being developed but are still facing great difficulties: administrative, legal and financial (Personal conversations with several of the members).
- The second trend is the formation of organizations in CBR project sites. The experience is being promoted by two organizations. It attempts to surpass the problem in the available parental organizations of being elite in nature and isolated from grass roots. However, the experience faces many difficulties among which is the weak and vulnerable position of the families which restricts their power and influence. In addition, these families are usually very marginalised , demoralized and burdened. They lack self trust as well as time and means . The process is to

be a long one among which empowering these people is a prerequisite to the success of the endeavour.

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