ATTITUDES OF FAMILIES WITH DISABLED CHILDREN TOWARDS THEIR CHILDREN AND THE PROFESSIONALS

Field Study

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Background

The disabled in Palestinian society, according to the statistics published by Palestinian Statistic Central Office, the registered disabilities with different types is 3% of the Palestinian society, this means in numbers about 120,000 persons are suffering the disability. We should add to the number the severely retarded cases and it's estimated at 70,000 cases, plus other disabilities that are not recorded with any involved institutions.

This group of people, and their families are marginalized for many reasons, and they need any type of guidance to How, Where, What, Who, and When, these are some questions related to the daily life of disabled persons and their families.

We intended to answer many questions starting with this WH questions, for this we discovered that we should go down to the roots, what is available, at present, for the families and their children? What are their actual needs? How they see their disabled children, in what content? How, what is their relation with bodies that serve this group?
Procedures.

Our first step was meetings as a team from An-Najah National University (Dr. Ali Habayib, Dr. Faisal Zanoon and Samer Aqrouq); we decided to carry the following:

1- Studying data available on the conditions of disabled.

2- Organization 2-3 meetings with people working in the field ( Union of Psychological and Social Workers, Red Crescent Society, Ministry of Social Affairs, Disabled Union, Rehabilitation Center, Ministry of Education, Blind People Association).

3- Meeting with parents of disabled (40-50).

The questions raised in the meetings were:

1- What disabilities we are working with?

2- What facilities are available?

3- What relations do we have with the disabled?

4- What type of relations we have with their families?

5- What do we offer the families and the disabled?

Starting with the disabilities question.

It's clear that the types of disabilities the attending institutions deal with are very limited to four major types.

- Different Physical Disabilities excluding sever ones.

- Blind (various degrees).
- Minor Deafness Disability.
- Minor Mental Disabilities.

Fact Found.

All institutions working with the disabled lack the major essential equipments needed for working with the disabled, except for 3 institutions who were able to obtain the needed equipments through donors.

The distribution of institutions according to disability was:

a- We have 12 institutions working with all types of disabilities.

b- Two working with blind.

c- Three working with physical disabilities.

d- Three working with deaf and speech disabilities.

e- Three with mental retarded cases.

The total number of institutions working with different types of disability is only 23 for more than 300,000, according to (PCS).

- Finding and locating fund, either from official sources, and or, other private, and donors is very hard and difficult.

- The absence of qualified people working with the disabled, except for some institutions.

Our next step was organizing meetings (3) with professional working in the field, 14 persons representing 12 institutions attended the meetings.
The questions raised in the meetings were:

a- Describing the services the institution offers.

b- Describing the attitudes of parents towards their disabled children.

c- How they can describe the relation between parents and their disabled children?

d- How they could describe the relation between the professionals and the parents?

The outcomes of the meetings were.

1- There is an urgent need for public awareness campaign towards the disabled rights and duties.

2- Awareness campaign with families, as professional stated, according to cases they have, 25% of the families report to the institutions to follow the cases and Development of the children.

Families only think, when reporting to the institutions that they should be given some money to aid them with the expenses of caring for the children.

3- Laws caring for the disabled are legalized, but not implemented due the political situation, and closure and difficulty of moving between cities to get needed care, and lack of funding sources.

4- The lack, and sometimes the absence of medical care for some cases, and in the case of mentally retarded using medicine as the only way of care.
5- Small number of institutions working with disabled call the families for meetings, and the result is creating a kind of carelessness and misunderstanding, and this affects the disabled only.

6- The role playing between families and professionals is absent, it's very important, in most cases, that treatment should take place at home and the institutions, and roles should be distributed according to the case, but this is not there.

7- The most important point was that professional don’t keep working with the disabled for long times, and they are replaced every now and then, this affects the disabled badly, confidence and trust wise.

8- Professionals state that the absence of adequate funding is one of the major issues.

9- There is a need for training on the most recent techniques with disabled and joint training with families.

Meeting the families.

The result of the meetings, beside the above mentioned points, was to call about 40-50 parents for a meeting at the university, 35 parent only attended, 12 professional, in addition to university participants.

The meeting took place in a very relaxed condition, and the questions raised to the families were.

1- Describe your relation with your disabled child?

2- Describe the relation with caring institutions and professionals?

3- What do expect as families from professionals?

We summarized the following remarks:

1- They were happy with the meeting as this was the first time somebody save time to listen to them, they said so.
2- 8 of the attendance refused the idea of having a disabled child; they said so in indirect way, though still they are making their best.

3- 24 fully accepted this as its something from Allah, and they could do nothing, they care very much for the children to satisfy religion obligations only.

4- 3 said they don’t know.

5- 25-30 said that there is not what you call professional care, for many reasons.

a- they don’t know were to find them.

b- Inadequate professional services in many cases.

c- Negative behavior of some professional.

d- Lack of knowledge and professional knowledge in many cases.

e. lack of the ability to guide the families.

6- Families, 20, said they never been guides by professional on what to do, and how to do it, or where to go.

7- Families, almost all, said that, the absence of governmental aid, in all aspects needed for the disabled is the major issue.

8- Absence of rehabilitation, and professional center in the country, only 3 centers covering all the West Bank, is one other critical issue.

9- The high costs of aid equipments, and medical treatment, making some families careless towards the disabled children, as they have other children to take care for.

10 Difficulty to join schools but to a certain age, and then left with no schooling.

11- Unfortunately there is a kind of mistrust between families and professional.

12- The complicated administrative systems in the disabled institution.
13- The big between the institutions objectives and the real objectives they could achieve.

We found out that more than 31 of the attendant agreed that most disabilities were caused due to medical faults, either during pregnancy period, or birth time or after, and no body is doing any thing concerning this.

Recommendations.

1- We recommend that a monthly meeting should be held, at least, between professional and families, in addition to other needed meetings.

2- There is urgent need for public awareness campaigns to change the way the society and related individuals see the disabled.

3- There is a need for composing a body to work in solidarity with disabled to make pressure on official to implement laws related to the disabled.

4- There is an urgent need for medical awareness campaign for explaining the danger of relative marriage, and for the early discovery of disabilities.

5- Supporting families with disabled children in all ways.

6- More training for processional should make in many topics.

7- There is a need for the unity of institutions working in the field may be according to disability only.

8- There is urgent need for building school, fully equipped, for those who are not having any chance of going to schools, the mentally disabled. This project is vital need for the mid and north of the West Bank, and should be talked over in more details k upon our meeting.

9- There is a need for more professional rehabilitation centers, and also medical rehabilitation centers.