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The Reality Faced by Handicapped People and their Relatives

Mrs. Josette Curmi
Parent, Representing the Parents' Society for
Handicapped Children

The Parents' Difficulties

I would like to set out some of the facts/problems faced by parents because of their child's handicap. These are the experiences expressed by parents during educational meetings organized by 'The Parents' Society For Handicapped Children' during these last six years.

When the parents realize that their child will not develop in a normal way they undergo a great shock. They cry, say its hard luck and think that they are the only ones with this problem. They enclose themselves in a shell and try to do everything on their own. This is a phase in life which everybody must go through.

Acceptance

Here the process of accepting their situation starts. This situation changes the life of the married couple, their life as parents and their social life.

Our reaction, at first is a confused one, that of not knowing what to do or where to start from. We hope that may be through time and prayer everything will turn out to be right. Prayer is important, because it helps you to accept the situation, but it is not enough.

Medical Help

We visit doctors and specialists in hospital and also at private clinics. Some of them help us and explain to us the facts as they really are, telling us that the child will not be normal but can make great progress. Unfortunately others do not help us at all.

Few of the doctors backed us up, encouraged us or else referred us to other doctors or specialists. But who is responsible to co-ordinate this work and ensure that the parents will continue working with their children? There is always the temptation for the parents to fall into a state of 'suspended passive depression' which might leave unhealthy effects on the children and the rest of the family.

One can say that we lack specialised doctors who are capable of understanding the problems facing our children. Their reaction is so negative that sometimes we have been told "there is nothing to do, but watch them grow." In fact there is a lot that we can do. We cannot face all this on our own. However, in one case where the 'History Sheet' of the delivery of the baby was asked for, this was not given to the parents by the hospital. When we asked how great is the brain damage they answered "pretty bad, but time is a great healer". Today we ask ourselves, "why didn't we ask for further details and support?" We were under shock, we could still not accept the situation, we were afraid, we hoped that the news was not true.

In such a situation how can one blame the parents if they do not turn up for the hospital appointments with their children? All contact between hospital and parents is lost. Are the parents personally followed and asked again to go to the hospital for their children's progress to be checked?

Our first advice to the parents of handicapped children is: do not be passive, don't let your child grow without your doing anything. Don't repeat our own mistakes. Everyday is important. You need a lot of courage, determination and patience. The backing up of the family is important but it is not enough because more or less, everybody is affected by your problem too. Look for professional help, educate yourself on the subject and join organisations of people sharing similar problems. Never think that a handicapped person is good for nothing. Every handicapped person has something to offer. You have to work hard and with the help of experts, specialists and therapists the talents of the handicapped child can be developed.

The second advice goes to the medical staff. "Don't pussy foot around with delicate news." Tell us the truth but please do not make it seem that the whole world is falling apart.

Every handicapped person must be studied and analyzed carefully. It is misleading to conclude that just because a child has a degree of brain damage, no development is possible. You have to help us move from one stage to another. In many cases the child develops in a normal way as other children but this development takes longer. We would like to mention an example concerning a squint. Certain doctors say that it is useless operating. It is true that this can be the case, but it will be better if specialised doctors, after performing tests, confirm this. There are cases where children were successfully operated. We insist that even if the operation is only

'cosmetically useful', unless it is detrimental to the children, it should be undertaken. Parents would like to see their children even just looking better and the children themselves would feel better accepted by society.

The same example can be applied to physiotherapy. Some say that the children need it while others say that physiotherapy is not necessary. There is often disagreement about what could be necessary therapy. Many times we have been told: "Why didn't you come before?" Now we will see what we can do because treatment is more effective when started at an early age. Other times we are told that it is too late.

We would like to ask the appropriate authorities to develop Prevention Child Care Programmes for all children in Malta. This will be the basis for the commencement of suitable programmes for the child's development if problems are identified. The lack of prevention programmes and subsequent assessment and adjustment of children programmes could mean regression as against progression of a child's total development.

What can we as parents do? We try everything because we love our children. It is of maximum importance that every visit we pay to the doctor is recorded on the file and that a copy should be given to the parents. In this way a lot of time is saved, the repetition of the same story is avoided. Most important, however, the condition and development of the child must be registered professionally, for continuing progress to be identified planned for and monitored and reassessed with essential programmes in action continuously.

From home to school

A very important age is when for the first time the children leave the home environment and go to school. The separation is great, the protection which we had offered at home will diminish. Handicapped children who are capable of attending normal schools should have full support from the Education Department too. It will be a great contribution for the children to integrate better in society. What are the attitudes and expectations of parents for the children's well-being at school? Love and dedication are very important. The first aim should be to teach them to be as independent as possible. A team of doctors and specialists should assess the children and plan a programme which should be shared and developed with the parents. One cannot possibly separate the parents from the teachers and say that at school what the teachers say shall be done and at home what the parents say shall be done. This will mix up the children. Parents and teachers should work together and in time and through patience, a lot of positive results will emerge.

We would like to see therapy as a part of a daily programme at school. This can be practiced through various ways. In the same way as therapists pass on information to

the parents even the school can receive such information. We would like the children to learn a lot of things - anything which is possible for them to learn - to be independent, self confident, to use their senses, to play and many other things.

The understanding of the behaviour of the children does not require a lot of intelligence but knowledge is important. Where possible let us do our utmost to teach them to behave themselves. How can we say that the children cannot do things unless they have been given the opportunity to learn to prove themselves? When the capabilities of the handicapped person are developed this will lead him/her to further independence from his family and eventually better integration within society generally. Education, both at home and at school, should contribute to give the children self confidence and more motivation in order for them to develop, experiment and to become creative all the time, despite their handicaps/disabilities.

Youths and Life in the community.

When the school education placement ends, the children are transferred to centres, sheltered workshops and some of them are given jobs. Every case has its own problems which should be followed and treated individually.

This last stage will not be difficult if the children had received adequate effective treatment from a young age. The child will move to a different provision but the new programmes at this place should be a progression of the past experiences.

In other State Schools there exists the 'Vocational Guidance and Counselling Service.' Is this service going to be extended for those youths with special problems?

Separation

One problem which really worries us is: "what is going to happen to our children when we die, will all our work have been for nothing?" We feel the need of Respite Care Homes where at least these children are kept for short periods of time in a small group, in an environment similar to the one we had given them at home. This service can be most useful even when the family is undergoing some kind of crisis or else is in need of some rest. In this way the children will be acquiring experience of living outside their family and this would prepare them for their eventual separation from the parents.

This thought of separation is something which breaks our hearts but something which is nearly certain to happen. Remember the advances of science, handicapped children are living much longer. Are our children being taught to become independent when possible? How far will it be possible for them to live their daily life, to work and

recreate themselves? We parents do not know what situation they will find themselves in and the thought terrifies us.

Necessary Services for Disabled Persons and Their Families.

We have come to the conclusion that the following services are necessary for Handicapped persons and their families:

1. A Preventive Child Care Programme for all the children of Malta so that children with special needs may be identified and assessed early in life so that they may receive the necessary treatment and rehabilitation.
2. Education and support for the parents so that they may be guided according to circumstances.
3. These children should be registered and adequate records should be maintained of the quality and quantity of handicaps etc. This will enable suitable comprehensive planning for quality services for the coming years.
4. Support for the families of these children is necessary. A system should be introduced whereby a social worker is assigned to every family at birth or onset identification of disability in order to help them face and accept the new problems and be able to take the necessary action.
5. A team of doctors and specialists who will continue to follow the child's progress in collaboration with the parents.
6. The Departments of Health, Education, Labour and Social Services should give their share in order to maximize the quality of life of the family and the handicapped person.
 - a. Laws relating to the handicapped person and his rights should be amended, implemented and monitored.
 - b. We believe that the study of the present administrative system could give definite insight for upgrading of present services without undue added expenditure, always for a better service.
 - c. Home and other adequate housing facilities for all families involved.
 - d. Help to parents who are getting old and have handicapped children.
 - e. The founding of Respite Care Homes, Day Centres, Centres for Modern Adult Training, and Sheltered Workshops and even Residential Homes for the Handicapped where they can live within the community.
 - g. Financial aid for the parents for the acquisition of aids and other things.
 - h. Updating of all held records.
7. The integration of children and youths in society.

In this way we have offered a clear picture of our feelings and needs. We think of these daily. We would like to encourage the parents present here, we thank all those who have listened to us and we hope that this will bear the desired results. We have done all this for the benefit and love for our children.