

# **11.**

## **Report of Three Workshops on the Individual, the Family and State Services**

### **WORKSHOP QUESTIONS**

- 1. a. What in our understanding is an independent life for disabled people?  
b. Do you think that a Special Transport Service will contribute towards independence?**
  
- 2. Parents are definitely bound to take important decisions which involve serious principles.  
What is necessary so that parents will be supported when taking these decisions?**
  
- 3. One of the biggest problems facing the leadership and implementation of planned policy is the staff problem.  
What should be done so that staff will be trained, feel motivated and personally responsible as a team member?**
  
- 4. ‘The greatest handicap is ignorance and the best therapy is education’. Comment.**

Participants agreed that the disabled person's dependence reduced the freedom of the carers. Thus if disabled persons can become more independent so too may the carers. Life will become easier for all involved.

The disabled person experiences so many mobility limitations. This of course is dependent on the nature, type and degree of the disabling condition but s/he must learn to make the most of his/her abilities. Independence training must start early in life. This would imply the need for motivation and maturity. Disabled youths who have been brought up under the influence of these attitudes can decide what they can cope with alone and they will recognise when they need help from others. Many participants however did come to the conclusion that the biggest stumbling block to independence is the parents' overprotection.

The concept of independence and interdependence was discussed. Disabled persons may be dependent on others for various functions like for instance personal care. But the required assistance should be aimed at increasing personal independence so that the individual can develop his/her maximal potential. The need for choice in the selection of services was also noted. It was felt that disabled persons should be allowed to exercise their independence by being able to choose the service of their choice. For this to be realised, it was considered necessary for the creation of flexible supportive services at all levels, i.e. to suit the real needs of disabled persons and their carers and not the perceptions of statutory service providers. It was also suggested that disabled persons should be given an allowance which would enable them to procure the services of their choice.

The group considered that one of the ways in which a disabled person could achieve independence, was by earning a living, although this was not the only definition of independence. In view of this, the group discussed terms of employment of disabled persons. It was generally felt that employers are automatically biased against disabled persons. All too often, they underestimate the intellectual abilities of persons with physical disabilities, who apply for jobs. Work colleagues may also show prejudice - again, often due to the fear that the disabled person will not be able to keep up with the desired output or carry the relevant responsibility. Disabled persons who are in employment are always made to feel that they have to work twice as hard to prove themselves. Education of the population at large is called for.

The group also felt that the state should devise practical ways of encouraging employers to take on disabled persons on their staff. Suggestions were, subsidies to companies, incentive grants, compensation to cover periods of sickness of disabled persons, for example because of prolonged hospitalisation or surgery. It was noted that the state already makes various concessions for pregnant women.

For many disabled persons, employment opportunities do exist, but transport to and from the place of work is very often the stumbling block. The group made various suggestions as to how this could be overcome:

- the state could employ someone to teach disabled persons to drive. Having achieved this, subsidies on specially adapted cars could be considered.
- the state could provide specialised transport from different parts of the islands on a regular basis. This may or may not be on a daily basis.
- organisations that already own specialised vehicles could be encouraged to make their services available to disabled persons. The state could contribute in various ways, eg. provision of drivers, petrol allowance, etc.
- the granting of a mobility allowance was also considered. Whatever system was adopted, the group felt that priority should be given to the most severely disabled. It was also held important for consideration of the need for family transport. In some cases, it is pointless thinking of transport for a disabled person alone. Disabled persons have families and friends, like everyone else.

While on the subject of transport, the group also highlighted the numerous architectural barriers that exist for disabled persons. The absence of dropped kerbs, lifts in public buildings, ramps and the like are very evident. This problem should be addressed in a serious fashion by the authorities concerned. There is no point in having special transport facilities if access is absent at the destination.

### **Organisational Needs**

The lack of staff to organise and develop services for disabled persons, according to formulated policies is a problem. What should be done so that the required staff is trained, motivated and feel personally responsible as part of a team?

The group stressed the need for well trained personnel. The major function of these persons would be to enhance and develop the social skills of disabled persons apart from contributing to other aspects of their well-being. It was felt that this was the most effective way of giving disabled persons their independence. Formal professional training was considered important, but this did not deny the contribution made by non-professionally trained volunteers and helpers. In reality, it was felt that the number of persons with the desirable mental, physical and emotional abilities required of persons caring for disabled persons, is very small indeed. Where personal care services are concerned, one could consider training caring persons in the correct skills and attitudes. Formal qualifications are not necessary.

On the more professional aspect of disability management, the group noted the complete lack of physical disability and intellectual disability teams. These teams are separate entities and should be considered as such. Such teams require the services of motivated and committed persons. Each should have sound basic training along

the correct lines and with the same philosophy. One well trained team could spread its philosophy more effectively than one person on his/her own, i.e. the multiplier effect.

It appears that the state services are still riddled with too many empire builders, each providing fragments of complementary services. Co-ordination of services is essential. Information sharing must be encouraged and stressed. It was noted by some members of the group, that individuals who wish to contribute to the development of services, through for eg, further studies, etc, often find major obstacles - either in terms of attitudes, hard headedness or finances.

The motivation required to improve the contribution of professionals to the care of disabled persons, could be their personal acknowledgement and recognition as true members of the multi-disciplinary team. Their involvement in assessing the need for services, planning and policy implementation and evaluation should not be overlooked. All too often, the persons in direct contact with disabled persons are never consulted or asked for their opinions. The response from all the personnel involved, is a measure of the attitude of the policy makers who often think that they know it all.

There should be more co-ordination and co-operation between the professionals, parents, relatives, friends as well as the community. Communication is more than lacking between societies, departments and people who really matter with the care, training and treatment of the handicapped person as well as his rehabilitation.

Education at all levels is a must. It aids prevention and should start from a young age. This will also help with regards the aspect of acceptance and integration of the handicapped. Public relations should improve from all sides.

An advisory service, centrally placed is much needed. It will help parents and all to have a place where queries can be made and accurate information given. An established list of the various professions and services available could be developed.

Listening and respect especially between the professionals on the island is so necessary for positive communication. Team work is essential as against the building of empires. More co-ordination between state and voluntary bodies should prevail and not just be in writing or beautiful appearances on T.V.

It is imperative that during their period of study, teachers, doctors, police, priests etc....take or receive proper education and experience regarding the Concept of Disability and especially its needs. Due to the bureaucracy that exists, students have sometimes been prevented from receiving experience in this field of study.

Parents should share their love within the family. Overprotection is a danger. Professionals also have to have a humane approach. Parents seem to run from one professional to another to seek help. Parents must realise the need to evaluate problems and needs and deal accordingly with them in order of priority and with the assistance of a multi-disciplinary team.

**Availability of Professionals:** There exist little resources in Malta. Quality of training is essential as well as better allocation of qualified staff for more efficient services. It is the professional aspect and integrity that has to be seen and not his/her political view.

Funds are essential. If properly directed more effectiveness could be achieved in the training of staff. Also what happens to all the reports...are they shelved?? Why are only a few implemented?

Should parents know all facts about their children's handicap as a right?..Should siblings have the same right?...What is actually happening?....How do they get to know the truth?....Do we always act when it happens (crisis management)...? We should be prepared by means of education and interest.

There should be more than one person specialising in a particular field. The state and the groups should be prepared to send people abroad to study. Scholarships and grants should be made available to whoever wants to specialise in a particular field.

It was also stressed that it is the Maltese specialists who can get the best results from regular work. It is rather useless to have foreign specialists visit Malta, do a couple of tests and take off again. They don't know our language and the Maltese environment, let alone the children. Nobody can afford to regularly take their children abroad for assessment and monitoring.

We are in the primary stages of planning....may be we should act more as a pressure group to press for requests in a proper manner to the right authorities. Pressure on M.P.s and media could be applied from all angles. There are people who work from the heart and thus we should strive to get these people working together. We should bear in mind the words we say to handicap persons and talk about:-

**"WE SHOULD NOT GIVE UP.....LET US SEE WHAT WE CAN ACHIEVE AND NOT WHAT WE CANNOT DO....."**

## **Ethical Issues**

Parents are forced into taking various important decisions, some of which involve serious principles. What is necessary to assist parents in making these decisions?

Essential to the realisation of any scheme devised to assist parents in matters involving major decisions, is a full understanding of the issues at stake, by all those concerned. Parents will be faced with numerous decisions - like any other parent. The major difference is that these decisions will be outside their expectations and outside their experience or that of close relatives or friends. In an unprepared service, such situations are also outside the experience or full understanding of the professionals concerned. Expert training of all professionals concerned is essential. All aspects have to be covered, i.e. the medical, social, educational, cultural aspects etc.

All too often, those dishing out advice and information about the care, diagnosis and prognosis for a disabled child, are either uninformed or ill-informed. It also happens that health care professionals are also uncomfortable about the whole subject of disability and its implications. This may be a reflection of an organisations' attitude to the concept and reality of disability in today's society. Health care professionals, (all levels) do not explore the meaning and implications of disability on the individual and the families concerned during their basic training. They never actually confront themselves with how they feel about disability, how they can contribute effectively to its management, and how they could help prevent it. What also appears to be lacking are the social skills required when dealing with disabled individuals and relatives of disabled persons. Poor communication skills are evident, although this may be a reflection of how inadequately we are all prepared to face the reality of disability and its consequences, in a positive and constructive manner.

Such an approach does not inspire confidence in persons whose confidence may already be at a low ebb.

Parents who are still trying to accept the advent of a disabled child into their lives, need support. They want to know the facts, although may be not all at once. They want guidance, but they don't want to be treated like morons. Each health care professional must be prepared to make time for these parents. Many matters will have to be repeated. Social Workers experienced in counselling are invaluable. They are also the persons who have access to information regarding benefits and support groups.

Right from the start, parents must be made to feel that they are the most important active persons involved in the management of their child's future. But they need supervision and support. A true and trusting partnership must be formed between them and the relevant professionals. No two families are the same. All have different values and priorities. These must never be overlooked or disregarded. Social and

cultural influences are very strong and no decision can be made outside the context of social and cultural behaviours. We live in Malta and Gozo - not anywhere else.

Parental expectations have to be explored. Sometimes these are unrealistic or on the contrary, an underestimation of their child's abilities. Such a process requires time and commitment. Involvement of persons outside the professional fields could be considered. Carefully planned peer counselling is invaluable and can take place in an informal atmosphere over a cup of coffee.

Time and support are essential. Parents must be allowed to express all their feelings towards their disabled child, be they positive or negative emotions. To do this, they must have a guarantee of absolute confidentiality.

## **Education**

The greatest handicap is ignorance and the greatest therapy is education. What do you think?

The above statements are true enough and there is still much to be done in educating the population at large about disability. The prevention and the reduction of the effects of disability also require more coverage. Disability awareness campaigns have much to offer. Early education at school, integration of disabled children in normal schools, seminars, poster campaigns, all have a part to play.

At the level of the professionals involved in the care of the disabled, this (i.e. education) must be a standard part of the curriculum. There is a need for the establishment of a post in Disability Medicine and Rehabilitation.

Rehabilitation services do not fall under any speciality at present, although some of the consultants would like to think that they have a sole and divine right to the use of rehabilitation services. It is found that rehabilitation services are constantly being stretched to meet the ever increasing demand, without actually meeting the real needs. A reallocation of resource is called for. Rehabilitation and Disability Medicine are still the Cindirellas of medical specialities. The authorities must recognise the need for this speciality, seeing that existing specialities, i.e. the consultants involved, do not appear to appreciate this point. Specialists in Disability Medicine and Rehabilitation Medicine could organise disability teams in conjunction with other specialists and health care professionals.

Such persons could also contribute most effectively to the academic side (and practical side) of undergraduate and post-graduate staff education.

While discussing education and the handicapping effect of ignorance, it is worth mentioning the need for a better standard of education for disabled persons. It is pointless discussing employment and independent living if disabled persons are not allowed or given access to all levels of education. Also, how can disabled persons be expected to demand and argue their rights if their education has not included elements of social and interpersonal skills? As for everyone else, these are skills that have to be learnt. It is all well and good for able bodied persons to go around and say what they feel should be done for disabled persons, but how about giving these persons the right opportunities?

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