

# 28.

## Comments from the Floor May 28, 1989

### **Profs. Mario Vassallo**

It shows that many ethical issues have emerged from the discussions like e.g. legal aspects etc. but we need to know the objectives for collection and use of this data for the register to be compiled well. Irrelevant material will cause problems, e.g. In the Housing Survey-generic questions re services required, were asked for, which in fact cannot be met. Is a request for a swimming pool at home going to be met? I doubt it. Dr. Chamie was here last week and after her many meetings with significant persons, her main stressed comment, was precisely this. "What practical use, as a working tool, will these registers have?"

### **Mr. Moses Azzopardi**

I feel that we should focus not just on one aspect of employment but also on mobility and the environment. We need to provide services for travel to work from home and access in general, so as to facilitate integration within society.

### **Dr. Elena Tanti Burlo'**

I would like to clarify some aspects re the recommendations being made by the Action Research Group.

1st Recommendation:- A child may need further check-ups. This is done by us with hospital.

2nd Recommendation:- A child needs a programme planned and implemented. This is to be done with us by: e.g. Occupational Therapist in hospital who will plan a programme and implement it for a group of 3 children.

3rd Recommendation:- Follow-ups are carried out by significant National Commission Members, e.g. Mr.G.Samuel for School in general, Mr.Vidal for particular school needs. Re social worker links with organisations, e.g. Caritas or Martin Micallef from the School Psychological Service links with the Centre.

We are trying to create a follow-up structure. Assessment alone is a useless exercise. We are also making longterm recommendations, e.g. a preliminary report has been prepared and sent to the Minister of Education.

**Profs. Felice**

Little has been said about prevention! Two types of handicaps exist both requiring different types of prevention.

1. Acquired handicap - one would have to examine circumstances of safety, but I'm afraid the concept of safety in the home, on the roads and at work is surely lacking in Malta.
2. Congenital handicap resulting from genetic factors - regarding prevention also, The registers to be compiled could contribute towards better planning for services of genetic and congenital defects.

The University supported by the W.H.O. is developing a programme for New Born Testing of various hereditary conditions. It is important that:

- a. Babies will get help immediately on identification of condition, so further development of handicap may be prevented through medical attention.
- b. Couples at risk may be identified, so through appropriate counselling, further births maybe avoided.
- c. The Register is a resource for statistics, training professionals and for research purposes.

**Mr. George Samuel**

Well said Profs. Felice.

Many children have accidents during their school years; at home, on the roads, during the summer madness especially after festas. In 1979, during the International Year of the Child, an Awareness to Childhood Accidents Programme was mounted. Posters were exhibited in prominent relative places. Maybe the time is ripe to mount this programme once again. Can the National Commission for the Handicapped put forward this request?

**Hon. Dr. L. Gonzi**

Naturally the National Commission for the Handicapped will take note of Mr.Samuel's suggestion. As a Commission member he has the opportunity to bring this up.

**Mr. Wenzu Dalli**

1. As a blind person, I would like to refer to Mr.Moses Azzopardi's point regarding mobility. Mobility questions need serious study and should become an integral part of childrens' studies.

2. Much is being done in this field but please can the bus stop outside the centre for social work be put back again? I use the bus service to Valletta. I have complained, but I have not found anybody to look after this matter.
3. Please make money recognition easier especially the Lm5 currency notes. Why do I have to ask somebody to tell me the value?

**Hon. Dr. L. Gonzi**

Thank you Wenzu, as usual he has hit the nail exactly on its head.

**Mr. Richard Cannataci**

A register is the basis for all planning. It seems that unless incentives are offered, people do not come forward for registration.

In 1955 it was said that there were 650 handicapped persons.

In 1958 Professor Damato on his own, had identified 638 blind persons.

It should be possible to compile the register and have same kept up to date by professional people. Of course, there must be various registers which together make up one whole. Incentives could be e.g. no pension unless registered, no schooling unless registered, etc.

**Hon. Dr. L. Gonzi**

Thanks to Mr.R.Cannataci. His point is very valid. The Commission has considered this point. The problem of incentives tied to Social Services is that only people registered, may benefit from these services and if anybody is not receiving a service, he will in fact, be excluded from the register. However it is a valid point that something along these lines should be developed.

**Dr. Joe Cannataci**

I was pleased to listen to the points brought up by Profs. Felice about Industrial Safety, amongst other forms of safety. During my delivery this morning re legal aspects, especially those concerning the Data Protection Act and the need for the reformation of the constitution and the right to protection of personal information, I could not mention other legal aspects, e.g. work and the handicapped.

I have recently been involved with a person (case now before the Court) who was injured at work.

Employers' Association representative, **Mr. Mallia Milanese** said this morning that it is difficult to find people to work. The majority of unemployed people are unskilled.

The acquired handicap of people who are unskilled can have cruel effects. Hence the importance of early education of children, of continuing education and adult education of the handicapped. These matters are not only concerned with prevention, and that prevention principles should be embraced by legislation, but also so that efforts will be forthcoming to prevent accidents. Not only should we have the possibility of going to court but something more important for this labourer, who has lost an arm, is that he cannot continue doing his previous work which could help him to reintegrate into society. We need to educate him, to help him and it is never too late to learn. Thus his dignity through work will be reacquired in a better way.

**Dr. A. Charles**

I thank the National Commission of the Parents Society for Handicapped Children. This Seminar has been very interesting and of great educational benefit for me - for many others I don't know. Professionals were recently sent a register of philanthropic organisations of the handicapped and we do have many organisations but the attendance of all these people is lacking. I expected them all to be here.

**Hon. Dr. L. Gonzi**

I appreciate this comment. One could have expected better participation from voluntary bodies and naturally, one of the first things that must be done is to prepare valuable reports otherwise it is no use organising seminars. It is important to analyse and study the various aspects, amongst which, that of attendance. Who attended and who didn't and reason for non attendance.

**Mr. Felice**

The Multidisciplinary Team is doing a lot of valuable extensive work in each case. However I fear that what is happening is that till they finish working at Wardija School, not only will a lot of time have passed but when they get to working at our school at St. Andrews, so much time would have passed that these children would have left school and others would have come.

There are many Psychologists, doctors and other specialists who could at least start assessing the children on the waiting list to start them off on a sound footing. This will at least solve part of the problem. I don't think this should cause any difficulties.

**Hon. Dr. L. Gonzi**

Mr. Felice's comment should be noted and perhaps Profs. Vassallo could comment on this later.

**Ms. Moira Ferry**

I would like to add further to Mr. Felice's comments re the Multidisciplinary Team:

1. I would like to know by what criteria was the team chosen and whether there is a pilot scheme. It will take ages to reach other schools.
2. We would like to know why is there one Social Worker, one Psychologist, one doctor. I mean there are so many social workers, so many psychologists, why just one Team?

**Hon. Dr. L. Gonzi**

Once again the nail has been hit on the head. Perhaps we should give Profs. Vassallo the opportunity to link up the comments we have just heard.

**Profs. Vassallo**

I do not wish to enter into polemics, however I would like to answer to some points.

The university's co-ordinating contribution of this project is firstly that a model is designed. This model will then be replicated in other areas. In other words it is not our role to solve all the problems connected with the impaired, handicapped or disabled persons in Malta. But our role is to demonstrate how a professional service can be delivered as never before. We hope that there will be many types of this team. They need not all necessarily be tied to the research project, although we are interested in the research aspect too. This is why it is called The Action Research Project, so that there will be immediate intervention. But we will also build sufficient data to be used as the basis for the identification of specialised pedagogi for effective implementation. However the real problem is the lack of personnel. There are not enough motivated people to do this work. This is not money making work, and I'm sorry to say, that I agree with Mr. Felice, that these people have not been forthcoming. Some professionals do not come forward, because they have inverted work ethics. They are only after earning good money. They are not interested in any job unless there are quick cash returns.

I am going to publicly mention a case when our group needed to link up with an orthopaedic surgeon in the hospital. I'm sorry that I have to say this publicly but this is fact. I'm sure offence will be taken because of this, but it's about time that we stop hiding facts in this country and be more open. This does not mean that the children are not being treated by an orthopaedic surgeon, but not through a special interest group. In fact I would like to appeal to whoever, whether parents, teachers, professionals and forgive me Hon. Prime Minister, I'm referring also to politicians, that there is a great need for the investment of more time and resources in this sector.

I appreciate the pleas for attention but sometimes it is difficult even to meet these significant persons. One would expect, not to encounter difficulties for meetings to be held. We are trying to create a model - after a year's work this model is working. I'm pleased to note the demand for this work, but the demand cannot come from the university. The university has been entrusted with a specific task, that of providing a model to demonstrate how information can be collected, then it is to be expected that other sectors will be designated to carry this responsibility.

**Mr. Frans Ripard**

As a handicapped person's brother and a professional in this field, as a nurse, as also a member of voluntary organisations I must say that there have been some very good comments made and excellent material to be debated upon. May be eventually improvements will be introduced.

But one crucial point that needs tackling in our country is the help needed by parents of 'children' over 40 years of age. As we are studying other matters, we must study this too - like for instance the kind of help that is needed for these parents especially like the services of Respite Care Homes to give parents a short rest. We know that in 10 years time these parents may die or may no longer be able to cope with their children at home - as is in fact already happening with some. We must think of the future and study the important steps that must be taken.

**Hon. Dr. L. Gonzi**

We know what a serious matter this is and how worried the parents of all handicapped children are. I can assure you that this is one of the aspects to which the Commission attaches a lot of importance. But as in all matters, you must appreciate that good personnel, specialised and with a vocation are needed for this type of work. This is what everything hinges on.

**Mr. Fred Bezzina**

I think we all agree that there is a shortage of personnel but I think that it is the lack of co-ordination, that is the major problem. I know a lot of handicapped persons who are being seen by various specialists but the relative work is not co-ordinated. I feel that with some effort, more can be done through the already existent services. However, I also feel that included in this model way of operation, parents should be an integral part of the team and I feel that, those parents who are able to contribute, should be included in the making of the decisions both during the planning stages and the implementation of the programmes.