

# Lejn il-Futur

Prinċipji u Policies  
għall-Persuni Handikappati  
u l-Familji Tagħhom

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## Principji u Policies Għall-Persuni Handikappati u l-Familji Tagħhom

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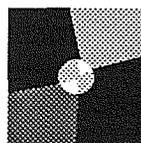
Proceedings of  
a National Seminar  
held on the 27th and 28th May 1989  
at the University of Malta



GHAQDA  
GĦALL-GENITURI  
TA' T'FAL  
HANDIKAPPATI



DIPARTIMENT  
TAS-SAĦĦA,  
MALTA



KUMMISSJONI  
NAZZJONALI  
HANDIKAPPATI

## Acknowledgements

It is right and proper to acknowledge the excellent contributions, by various members of our Society, towards the National Seminar and the publication of its proceedings. It is not possible to mention each person by name, but the reader is directed to the names spread throughout this publication. Some key contributors, however whose name is not mentioned will be identified. Others will be referred to collectively.

The Parents' Society for Handicapped Children represented by Mr. M. Pisani, Mr. A. Abela and Mrs. J. Xuereb met Dr. L. Gonzi together with Dr. L. Minster, Dr. J. Cannataci, Profs. A. Cuschieri and Mr. F. Bezzina on 9th April, 1989. The idea for Seminar was openly accepted.

Ms. J. Xuereb and Mr. F. Bezzina were responsible for the planning and coordination of this seminar. They were joined by Dr. G. Galea to publish these proceedings. They were backed by the National Commission team workers who are Ms. R. Fenech, Ms. C. Camilleri and Mr. A. Sacco. Mr. F. Ripard was of a great support on the last few days before and during the Seminar while Ms. V. Schembri from the Health Education Unit was a great help in the typing of the proceedings. Ms. M. Azzopardi, Ms. A. Cortis, Ms. C. Grech, Ms. T. Pace and Ms. S. Vella helped in formulating workshop scripts and do their transcriptions. The Department of Information also helped by making their computers available.

As you will notice from the programme many people delivered papers, chaired sessions and facilitated and reported back the proceedings of the workshops. All their names appear on the programme and accompanying the scripts. Each excellent contributor including his Exc. the President, the Hon. Prime Minister, and Ministers are thanked personally.

The University Rector and all University Staff who helped are also to be thanked.

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Finally a word of thanks to the audience who participated in this Seminar, and to all readers of this book. We thank you for your part and future contribution.

# Contents

1. Opening Address Dr. Vincent Tabone	1
2. The Reality Faced by Handicapped People and Their Relatives Mrs Josette Curmi	5
3. Attitudes and Needs for an Independent Life Mr. Tonio Mercieca	11
4. The Reality - A Chain of Decisions Mr. Fred Bezzina	15
5. An Overview of State Services Dr. Ugo Mifsud-Bonnici	19
6. An Overview of State Services Dr. L. Galea	23
7. Health Services for the Handicapped Dr. G. Hyzler	29
8. An Overview of State Services Profs. John Rizzo Naudi	33
9. The National Commission for the Handicapped Dr. Lawrence Gonzi	37
10. Disabled People and the Community Dr. Louis Minster	45
11. Report of Three Workshops on the Individual, the Family and State Services	55
12. Report of a Workshop on the National Commission for the Handicapped	63
13. Report of Four Workshops on Improving the Quality of Life	67
14. Comments from the Floor May 27, 1989	73
15. Registers of the Handicapped as Statements of Needs and Rights and Not as a Stigma Profs. A. Cuschieri	75

16.	Computers, Law and a National Register of the Handicapped Dr. J. A. Cannataci	79
17.	Employment in the Public Sector as a Statement of Dignity Mr. E. Cilia Debono	87
18.	The Dignity of Work and the Problems Faced by the Handicapped During Employment Ms. Catherine Azzopardi	93
19.	Employment as a Declaration of Dignity Mr. Richard Cannataci	99
20.	Employment as a Statement of Dignity Mr. Laurence Lautier	103
21.	The Handicapped and Employment Mr. A. Mallia-Milanes	107
22.	Working With Parents - A Community Doctor's Approach Dr Sarah Portelli	111
23.	A Look at a Multi-Disciplinary Team of Professionals working with Parents as Partners Ms. Maureen Cole	115
24.	Action Research Project Dr. Elena Tanti-Burlò	119
25.	Report of a Workshop on Registers for Disabled Persons	123
26.	Employment as a Statement of Dignity - Workshop Report	125
27.	Report of Four Workshops on Multidisciplinary Teamwork	131
28.	Comments from the Floor - May 28, 1989	139
29.	Closing Address Dr. E. Fenech Adami	145

## Preface

Dr. Louis Galea  
Minister for Social Policy

It is my great pleasure to share a few thoughts with you, before you start delving into studying the proceedings of this seminar.

When in 1987 we were entrusted with the governance of our country, the responsibility for Social Policy was distributed between the Ministry of Education and the Ministry for Social Policy. The Ministry for Social Policy was entrusted with ensuring that the approach towards the attainment of the twin objective - basic equality and maximum individual care - will be as integrated as possible. These objectives were established after looking closely at the complicated development, by successive governments, of the Welfare State.

I strongly believe we need a new direction, namely an orientation towards the development of a Welfare Society. The time is ripe for our country to move away from the rigid institutions and a bureaucratic administration, which had the effect of social services becoming depersonalised. We must move towards a more flexible and personalised but integrated system of social services.

Although our country - as compared perhaps to other larger countries is somewhat small in size and population, we are still faced by negative attitudes instilled by the old system. Change does cause resistance but we must together look and work towards change with a positive outlook and broad vision.

Government has the responsibility to safeguard, create with others, and monitor the most conducive environment for the well-being of citizens. We can talk at great length about the implications of social justice, social solidarity and equality. But we must also realise, that each person has different needs and receives the effects of these noble values in various ways. Therefore, needs must be met by services developed within the framework of integrated policies and systems.

The National Commission for the Handicapped, openly extended its support and partnership to The Parents' Society for Handicapped

Children. This is part of the function and role of the Commission, whose role and function, in turn, mirrors the democratic principles of government.

We must work together from our various social network groups, the state, the voluntary bodies and other significant institutions. Together we can co-operate, in a spirit of active dialogue and study, so that the integrated policies can be developed from the grass roots upwards, to effectively meet the diverse personal needs of individual citizens in our newly created Welfare Society.

# **Parents' Society for Handicapped Children: Introduction**

Ms. Joanna Xuereb  
Social Worker

## **The Development of the Group**

It is important to expand briefly, and put into context the objectives, functions and role of The Parents' Society for Handicapped Children, and the role the group has played, in the joint development and organisation of this national seminar.

The Kindergarten for the Handicapped (Parents' Group) was established in 1976 by Miss Frances Ryan and a group of five parents, under the patronage of Mrs. Moira Mintoff. At that time there was no school provision for these young multiple handicapped children.

In October 1987, a new name and statute was embraced by the existing members.

The Parents Society for Handicapped Children is an active philanthropic, non-profit making organisation with the following aims:

1. to provide support to handicapped children from birth;
2. to assist, support and educate parents of handicapped children and help them to overcome the difficulties encountered through their children's handicap;
3. to organise and carry out such functions and activities deemed necessary to accomplish 1 and 2 above, and to bring together all persons interested in the welfare of handicapped children.
4. to serve as a means of liaison between handicapped children, their parents and official authorities and professional persons;
5. to create a public awareness of the handicapped and their problems.

Membership includes 250 parents of children and adults of diverse ages who experience various types and degrees of impairments, handicaps and disabling conditions. The membership also includes a few professional people and others interested in promoting and working towards the resolution of various problems and needs.

Throughout the group's work, over the years, efforts to reach parents on an individual and group basis, have been regular, intense and innovative. The various supportive, advisory and counselling services, educational and social activities undertaken, have been key contributing factors for bringing parents, with a common need, together.

All these efforts, have been conducive to building a strong and cohesive community spirit, within this national group.

This community spirit, has also extended outwards as a communicative, collaborative working partnership with other important and necessary social networks.

The group has discovered its useful and important role in keeping close contact with its members, but reflecting the aims of the statute, the group has been instrumental in conveying to national and other networks, the problems and needs faced by disabled people and their families. The Group and its members constantly contribute towards development and evaluative processes in whatever has been happening in the field of disability.

### **The Journey Ahead. An Internal Report**

During the Summer of 1988 an internal group report entitled 'The Journey Ahead' was developed. This report 'The Journey Ahead', is a developmental account of the work and activities of the Society. It is a report based on the elements experienced through the parents' daily lives, as clearly demonstrated through the Specialised Family Life Education Programmes developed, organised and documented by The Parents' Society for Handicapped Children. Included in this study is the philosophy and methods underlying this education and an outline of family and societal problems, with projections for the further development of the Group. The conclusion deals with a brief outline for global plans and particular suggestions for general redevelopment and future long term planning of facilities and services for disabled people in Malta.

These services need to be collectively planned, for global policies to be developed, for the effective delivery of quality, personalised, comprehensive and integrated services and facilities.

The concise and insightful information contained in this report became a responsibility that just had to be shared with and discussed between significant professionals and institutional members, disabled people, their families and others.

### **The National Seminar**

The chairman of the National Commission for the Handicapped, Dr. Lawrence Gonzi, who had already shown great interest and openness towards various points of this report, was approached by the Parents' Society for Handicapped Children, with the

express aim of sharing these findings and putting forward a formal request for a jointly organised seminar on significant issues, to be held before the 1989 Summer Break.

The Seminar entitled 'The Journey Ahead' - Principles and Policies for Disabled People and their Families' was held at the Assembly Hall of the University of Malta on Saturday and Sunday 27th - 28th of May 1989. The Seminar was attended by 200 leading and professional members of our Society, as well as disabled persons and their families.

The seminar was based on a reflection of values, most notably Social Justice and Solidarity, for the promotion of a quality of life to be experienced by all involved i.e. providers and recipients of services.

This seminar created a forum for discussion and evaluation of issues facing disabled persons, their families and the environment, in the light of the effects of modern science and technology, as being experienced at present, and to be experienced by all concerned, at a higher and broader level, in the future.

The realities facing disabled persons require close study at various levels as a priority during the planning stages of principles and policies for the journey ahead.

There is a great need for the awareness and global knowledge of the already available state and other services so that further planning strategies for the requirements and development of unified, comprehensive, modern and quality services, will be possible.

But, what are the necessary values and requisites that promote a quality of life for disabled persons and their families as members of the community?

These proceedings contain the programme, full script of all papers delivered, workshop reports and comments from the floor. The seminar proceedings are being published to spread awareness of these issues and as a tool for further indepth study.

### **Acknowledgements**

There have been so many people involved in the development and organisation of this seminar and the publication of the proceedings, and so many leading significant people willingly gave their full and untiring support, throughout this exercise of enthusiastic, direct dialogue between everybody.

We are truly honoured and grateful for each and every effort.



# 1.

## Opening Address

Dr. Vincent Tabone  
President of Malta

**Thank you Dr.L.Gonzi and thank you all for giving me the opportunity to open a Seminar which I will think is well-timed, and which can be of help to all of us. In my opinion it took us some considerable time to realise that handicapped persons possess the same dignity as the rest of us, and that they should have special rights so that the community can make up for their handicap. We all have a duty to perform in respect of our handicapped brethren.**

Naturally there are people present here who are better versed in this subject than myself but as an introduction to the seminar one can say that physical or mental handicaps are sometimes present at birth through a genetic disorder or acquired through some accident or disease. People who are handicapped from birth are aware of the disadvantage brought on by their handicap, but gradually and progressively, later on in life they realize more fully the difficulties facing them. Those who are suddenly faced with a handicap through some accident or disease are initially shocked by this new situation, and this trauma is felt more at the beginning because - consciously or sub-consciously - these people start making comparisons with the situation as it was before the accident or disease, when they were still fully fit.

But in time both these categories merge, so to speak, because they both find themselves facing the same difficulties that the so-called “normal” people do not face, and thus they fall into the same category of “disabled”.

We must also admit that our society - like all the others in the world - has registered enormous progress in this field. Most of us are aware that in Biblical times, when a person was born with a particular disability, or even when that disability was acquired during life, this

person was considered as a scourge sent by the Almighty to punish that same person or his or her parents. Suffice it to mention the isolation of these disabled persons who were even often faced with unjust laws; the lepers of old, the unclean, God forbid, if you were to approach one of them. But even the lepers of more than 50 years ago when I had just graduated as a doctor, were confined by sentence of the Governor, in those days they were treated as if they had committed a crime, and they weren't freed, if not after a long and arduous process.

The same applies to the insane. They were isolated from society - because society was pre-occupied principally with having its liberty restricted by people who inevitably exacted from it sacrifices and hardships. So more the reason to isolate these people.

I do not wish to enter into all the cases of mental illness or methods of treatment - where even today these methods have improved - but I would like to recall - for the benefit of medical practitioners present today - the use of the straitjacket, the violent way these patients were restricted in their movements, and how even in their most lucid moments they were treated as 'dangerous' people. Nowadays considerable progress has been registered and for this we thank our own social development which has not been lagging behind other countries. *We should* develop a sense of justice but we should bear in mind that we are at the initial stages and there's a lot more to be done! Moreover today I would like to accentuate briefly the duties of State and society in general. Let us begin with society - our society - in which Government, in principle, accepts and, in part at least, satisfies this need through legislation dealing with financial aid and various other benefits. Nowadays we have laws which give the right of work to the handicapped, and this is a right and not charity. Pensions are constantly being increased. All Administrations try to increase benefits. These people require assistance in housing, and much more help where jobs are concerned; they need transport facilities to and from work as well as when leaving home to carry out their social commitments.

In our country there exist societies like id-Dar tal-Provvidenza and other voluntary associations of which we have many, and which I am not going to mention by name for fear of leaving someone out, and they all deserve praise.

There are other organisations which look after the handicapped during the day, providing them with work, helping them to become independent even financially. Work means dignity to the handicapped not only because it provides the means to subsistence, but because it makes him feel that he is contributing something to society and that he is not there "under sufferance" or through charity. He *can* produce and *he can* contribute too. In many cases physically handicapped people possess brilliant minds and they are aware that - given the chance - they can produce exceptional results.

The phenomenon of the parents of handicapped children, feeling a sense of shame or guilt, is something of the past, and today they no longer hide them from society, except perhaps in some isolated cases. We too had some extreme cases. So I thank God and pray to Him firstly to inspire in each one of us a sense of kindness and solidarity towards everybody but particularly towards those most in need. We should be inclined to see what more we can do, while at the same time acknowledging what Government, voluntary associations and individuals moved by compassion are doing - let us remember not to act in a condescending way when dealing with handicapped people, such as "all right, let me give you a helping hand." These attitudes can irk some people. On this subject there exists the need for more efficient study on the integration of the handicapped, in society, work, education, productive level and so on; we should prove to them that we consider them as equals, with the same dignity as everybody else, having the same rights - and perhaps more - than we possess. We would thus not only be doing something worthwhile for these our brothers and sisters, but we would also be doing an honour to our country as befits a civilised nation.

A Seminar such as this is going to give a chance to all - including specialists in the field who are today present - to delve into detail and see what can be done, what proposals to present to politicians and government, on how to further assist existing voluntary societies and the possibility of having more voluntary societies. Personally I believe a lot in voluntary societies. I am not absolving Government of its obligations - every government has its social obligations which it must carry out, and it is already a good thing that our governments have already recognized this commitment - but voluntary associations, precisely because they are not compelled to offer certain services, but offer them just because they feel inclined to; and you will agree with me that services offered on a voluntary basis are worth double those, which are given by anyone who is just doing his everyday duty.

I encourage you all and I repeat that these (organisations) are a feather in the cap of our society and is an indication of a progressive society.  
I wish success to this Seminar.