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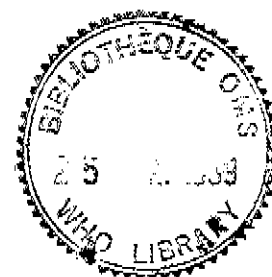
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The Rights of the Elderly with Mental Disorder  
Implementing action in the Region  
- The Scottish Example -

Prepared by

Dr W.D. Boyd  
Mental Welfare Commission for Scotland  
Edinburgh, United Kingdom

on behalf of the  
World Health Organization  
Regional Office for Europe



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## TARGET 4

### Reducing disease and disability

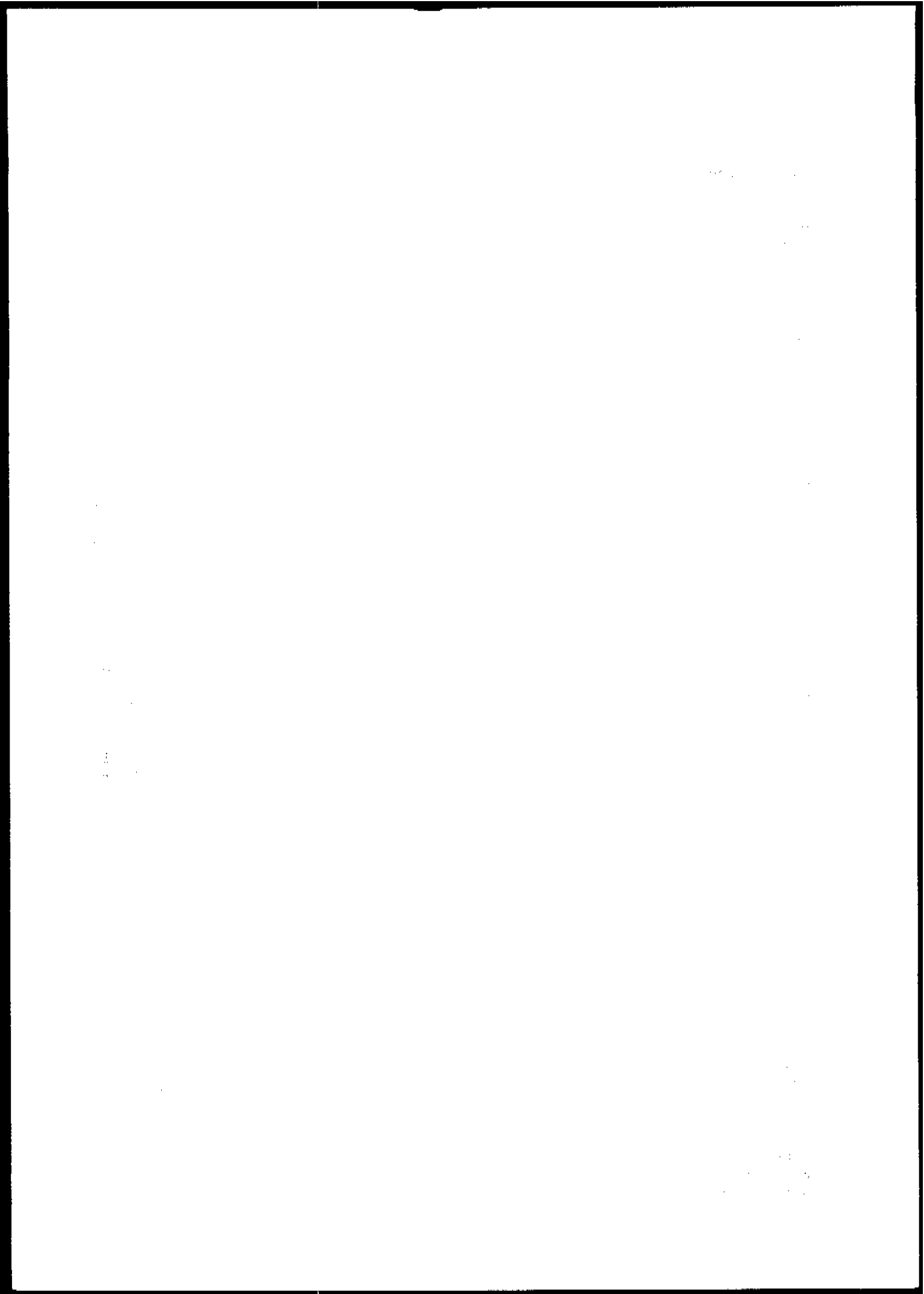
By the year 2000, the average number of years that people live free from major disease and disability should be increased by at least 10%.

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HEALTH SERVICES FOR THE AGED  
HUMAN RIGHTS %LJ%  
MENTAL DISORDERS  
AGED  
SCOTLAND

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## 1. Introduction

The care of elderly people suffering from dementia is now securely established as an area of major concern for all those involved in the planning and provision of health services.

Much has been written and discussed. Epidemiological factors have been recognized, the logistics of service provision have been examined and research opportunities have been set out. However, as more active steps are taken to develop services for dementia sufferers, it becomes apparent that questions arise about the rights of these individuals - the right to have access to basic care or the right to refuse such care, the right to retain responsibility for financial and domestic affairs or the right to have these responsibilities dealt with by others.

It emerges that the law is often unclear about these matters and that individual professionals - doctors, nurses, social workers and lawyers - are often left to make their own interpretations of what is required without the backing and the support of any defined legal policy. It is not surprising if, as a result, critics complain of unnecessary paternalism or of insensitivity to the real wishes of the old person, while professional carers become anxious lest their responsibilities are undermined and their best efforts subject to later litigation.

## 2. Recommendations of the Working Group on Prevention and Reduction of Mental Health Problems in the Elderly, Groningen, 29 April-3 May 1985

As part of the WHO Regional Office for Europe programme on mental health and in association with the Government of the Netherlands, a working group held in Groningen in April-May 1985 had examined mental health needs of the elderly, taking particular note of the interventions and management techniques which might obviate or reduce these needs. One of the important conclusions reached by the group had been that guidelines should be developed at national and international levels to cover the rights of those who, by reason of their impaired mental state, might no longer be capable of managing their own personal or financial affairs, or might require to be detained in an institution. A summary report of the working group is attached as Annex 1.

## 3. Follow-up of the recommendations in Scotland

At the same time two groups in Scotland were looking at this problem. The Mental Welfare Commission for Scotland was a body established by the Mental Health (Scotland) Act of 1960 and given an enhanced role in 1984 when the new Act was introduced. The Commission is given the duty "generally to exercise protective functions in respect of persons who may, by reason of mental disorder, be incapable of adequately protecting their persons or their interests." In practical terms this means that the Commission has had to examine the ways in which individuals suffering from dementia have had their financial and legal affairs supervised and also the extent to which they may have been detained in a hospital or other institution without the benefits of supervision and control which are provided for those who are detained against their will under the Mental Health Act.

More recently, Scottish Action on Dementia (SAD) has been set up by representatives from a variety of professional and voluntary bodies in Scotland in an effort to provide a catalyst for much needed developments in service provision and public awareness in the field of dementia. This group,

too, has given attention to the shortcomings in the present legislation as it affects people suffering from dementia.

On the initiative of the Mental Welfare Commission and with the encouragement of SAD and the active support of the Regional Office, a workshop was held in Edinburgh on 19-20 November 1987 to take further the recommendations of the Groningen meeting, to explore the extent to which existing measures dealing with the rights of elderly people with mental disorder were adequate and to determine whether additional measures might be called for. It was recognized that any proposals arising as a result of the meeting could not be acted on immediately, but it was hoped that the conclusions reached by the workshop would help to raise wider interest in the subject, that they would lead ultimately to changes in legislation within Scotland, and that they would also be of relevance to services in other countries.

4. Workshop on the Rights of the Elderly with Mental Disorder, Edinburgh, 19-20 November 1987

Participants included representatives from a variety of Scottish statutory and voluntary organizations having responsibility for and specialist interest in the legal protection of the elderly and the mentally disordered. In addition, three experts came from England and four from other countries to share in the meeting and to contribute their own experiences to the discussion (see Annex 2).

Dr J.G. Sampaio Faria represented the interest of the Regional Office, and the meeting was chaired by Mr P. Millar, Chairman of the Mental Welfare Commission.

A basis for the discussion was provided by a paper prepared by a SAD working party and presented by Dr R. McCreadie, which set out the position in Scotland.

4.1. The problem

A significant minority of the increasing elderly population are afflicted by psychiatric disorders, both functional and organic, which reduce or remove their ability to take reasoned decisions. The most important of these disorders is senile dementia, where gradual deterioration, occurring over months and years, leads to the appearance of many problems including physical danger, personal neglect, adverse effects on others and inability to cope with business affairs. The vast majority of those at risk continue to live at home, but some 10% require care in residential accommodation.

4.2. Protection of financial interests

At an early stage of a dementing illness, individuals may still be competent to look after their affairs or to instruct someone else to act on their behalf, and some form of mandate, often a power of attorney, may be used. With progression of the illness, however, the legal position becomes less clear. The enduring power of attorney, used in some jurisdictions (though not in Scotland) allows a mandate to be given in advance of failing mental powers; but it has some drawbacks, and it is only with the formal appointment of a Curator Bonis that financial interests are legally protected. Unfortunately, because their estate is limited, a curatorship is not a practical proposition for most mentally disordered people whose main income is derived from a pension and supplementary benefits. It is,

acknowledged that representatives are allowed to collect pensions, that hospital managers have duties to deal with the financial affairs of patients who are incapable of acting for themselves, and that social work departments have powers to deal with immediate problems. Nevertheless, there remains concern that legally supported and adequately controlled measures to deal with all areas of finance are not available.

#### 4.3. Protection of welfare

Only a very small number of the elderly with mental disorder are dealt with under the Mental Health (Scotland) Act 1984. Sometimes the powers within the Act to detain people in hospital against their wishes are invoked and sometimes the very limited powers of guardianship are used. In such circumstances there is statutory supervision of the individual and a statutory right of appeal against detention. In addition, the National Assistance Act (1948) allows the removal of an individual from home on account of grave chronic disease or insanitary living conditions and there is a possibility of judicial appeal against this also.

Most often, however, individuals being taken into residential care, whether under the supervision of the health services or private home managers, are taken there on an informal or voluntary basis, with no access to an independent review. Theoretically, they can discharge themselves but, in practice, they are unable to exercise that right.

#### 4.4. The need for reform

It was the view of the SAD working party that any individual who is legally incompetent should have a legal right to comprehensive care and protection, and that any intervention should respect dignity and be the minimum necessary. Reform of the present system of safeguards should include the requirement that there should be a single legal procedure leading to expert and comprehensive consideration being given to the needs of each individual. Furthermore, it is important that representatives of the local community with relevant knowledge and experience should join with professional workers in making decisions which will have the effect of limiting freedom to live independently.

#### 4.5. A proposal for a new procedure

It has been suggested that modifications to the present law would provide an adequate safeguard for those presently at risk; but it is the view of the SAD working party that an entirely new procedure is required and it is recommended that within each regional authority in Scotland there should be set up a mental health panel and a mental health reporter along the lines of the present children's panel system, with legal powers to supervise and give orders for the proper management of the financial and personal affairs of those elderly people whose need for protection is brought to their attention.

In presenting these proposals to the workshop, Dr McCreddie emphasized that legislation was required which went beyond that which was now available, and which offered protection against both too little intervention and too much intervention.

In putting forward suggestions for a change in the law, it had to be recognized that while doctors and social workers with responsibilities for the care of the elderly might give attention to the special problems and the special needs of those elderly people, consideration of a legal procedure as

innovative as a mental health panel might, in legislative terms, be required to encompass the interests of a wider group of people at risk, including younger people with mental illness and with mental handicaps.

#### 4.6 Views from abroad

The extremely valuable reports of the position in the Netherlands, Norway, Switzerland and the United States of America confirmed and strengthened the view that present legal provisions do not cover adequately the particular needs of the elderly. It was evident that in these countries questions are being asked similar to those raised in the United Kingdom and that there is a widespread wish to establish a new legal framework which will be more relevant to these needs.

In the Netherlands, for instance, the Insanity Act of 1984 leads to almost all elderly patients being admitted to hospital as informal voluntary patients at the behest of relatives or a curator, without the safeguards which would be available if their admission had been involuntary. Yet to think of establishing a more formal legal process for all those dementia sufferers requiring admission to hospital raises major risks of overwhelming the legal system and of incurring prohibitive costs. Curatorship and protective administration are means of dealing with financial and personal matters but they are expensive to introduce, and a new mentorship scheme to deal with all personal affairs is at present being considered.

In Switzerland, much attention is paid to the European Court of Human Rights, and the protection of the elderly includes controls at three different levels of restriction, thus allowing the individual to retain as much of his or her legal rights as is possible.

Provisions for legal supervision of those with mental disorder in Norway are made in four different laws at present and there is a wish in some quarters to concentrate these separate provisions into a single law. Interestingly, however, the proposals for general mental health legislation do not attempt to identify particular problems for the elderly in the belief that this would constitute discrimination against them.

In the United States of America it is recognized that there will always be conflict between on the one hand the desire to encourage autonomy and on the other hand the wish to provide the support of beneficence, often seen as professional paternalism. The many recent changes in the position of the elderly - demography, family structure, de-institutionalization among others - has forced society to review the present law, to take note of the vocal protests of the older citizens against too much restriction on their autonomy and at the same time to note inconsistencies and gaps in the present legislation. Power of attorney, informal guardianship, and traditional guardianship are recognized and the value of a limited guardianship, in which the level of responsibility is set out quite formally according to an accepted scale, has been proposed. Further measures which are being examined in the United States of America include services which offer help to the individual at risk without necessitating the use of formal legal controls. Help with banking arrangements or property arrangements, the development of a voluntary adult protection service, the use of the living will to specify wishes in the event of terminal illness, and the preparation of an enduring power of attorney which includes the nomination of a specific guardian - these are all approaches of interest and relevance.

#### 4.7 Views from England

It was evident from the three contributions from England that, while there may be differences in the law between Scotland and England, the problems for those dealing with the care of the elderly with mental disorder are very similar, and some of the general and specific points raised by the speakers were taken up by those contributing to the general discussion which followed.

#### 4.8 Discussion

Any consideration of senile dementia must recognize that this condition may present itself in many ways and may, in its earlier stages, be a diagnostic puzzle for doctors, who may differ in their views as to whether people showing obvious features of dementia are suffering from mental illness. This may lead to difficulties in making use of the provisions of present mental health legislation, especially if concern about precise diagnosis overrides acknowledgment of the presence of mental disability.

To take the view that someone is either wholly competent or wholly incompetent to manage their affairs is to avoid the reality of the situation where decisions are being made about the need for intervention. Many old people are partially competent - being competent in their day-to-day routine, yet unable to deal with major decisions affecting their lives. Their autonomy must always be respected, and perhaps the term vulnerability is easier to use than competence, for evidence of vulnerability - for example, to physical dangers or to undue influence from others - can be demonstrated and stated in a precise way.

It is not necessarily helpful to discuss the subject in terms of legal rights, for it is absurd to think that the many needs of the vulnerable elderly can be enforced by law. It is more useful to talk of social justice for the elderly, and to ensure that throughout the country there is equal care for those with equal needs.

What should be looked for is a situation where good clinical practice, adequate facilities, appropriate monitoring of care or suitable management of finances should be encouraged and supported by legislation. A good example is the Disabled Persons Act (1987) which allows for an authorized representative of the disabled person to seek information on his or her behalf. Another sensible legal view is that the enduring power of attorney can still properly be introduced, even when an early stage of the dementing process has been reached.

Sometimes it seems that legislation gives insufficient support to the needs of those at risk. Thus, the Court of Protection and the Curator Bonis deal with the estate rather than the practical needs of the patient, and guardianship under the present Mental Health Act allows only very limited control over the life of the person at risk and none at all over his or her estate.

Any new legislation must take account of the progressive nature of dementia and should consider whether the staging of powers, whether of guardianship or of professional intervention, may be feasible.

#### 4.9 Conclusions

During the group discussions which followed the presentation of papers and in the plenary session which concluded the workshop a number of themes were seen to be of major importance.

The obvious conflict between autonomy and coercion must be recognized in any consideration of the legal rights of elderly people and of their need for social justice. A principle to be upheld in any proposed legislation is that the more a measure erodes independence, the more necessary is it to have a mechanism for formal legal protection.

Before embarking on any new legislation it is worth examining closely the present legal framework to determine whether it is being used effectively. It may emerge that legislation appears unhelpful only because resources are inadequate or because there is a lack of consensus among professional carers as to how to make the best use of legislation and resources. The concern which some people have about de facto detention in hospital may be misplaced if independent monitoring can demonstrate that care is satisfactory; and such monitoring, if it encompassed those living in residential homes, including private establishments, in addition to hospitals, would meet some of the present apprehensions, though there would still remain concern about the adequacy of supervision of those living in their own homes or with family.

Turning to financial matters, the responsibility presently given to health board managers to concern themselves with the finances of their patients might usefully be extended by minor legislative changes to cover local authority services providing care for elderly people.

Legislation must take note of the effect on family and neighbours of disturbed behaviour in an elderly person who is mentally disordered. It may be admirable to maintain minimal interference in the life of an individual citizen, but if this leads to deterioration in relationships with those round about then ultimately there will be withdrawal of support. The possibility of independence is then eroded still further.

In acting against the wishes of a person at risk it is worth considering what the wishes of that person would have been in the pre-morbid state, and whether advice about treatment and care would at that stage have been accepted.

Proposals for new legislation must provide for enabling rather than restricting powers, which should not be frustrated by financial barriers. No new measures should be introduced without adequate research into the effects of change. Every effort should be made to provide pre-retirement education and information services which would encourage elderly people to make use of any new provisions under the legislation such as the enduring power of attorney or the living will.

Legal powers to intervene in the personal affairs of an individual should include emergency short-term measures, followed by longer-term measures requiring full or legal consideration. Consideration must also be given to the extent to which legislation will allow for the exercise of personal judgment by an assessor, or how far decisions should depend on formal criteria. There seems value in leaving open the possibility of examining each case individually and of taking note of specific problems.

There is a strongly held view that any new legislative measures which involve the monitoring of care provided for a mentally disordered elderly

person must cover everyone at risk: the law must be seen to be applied in an even-handed way. However, there is an equally strong view that in the great majority of cases the needs of the client or patient may be adequately met by a properly constituted case conference involving those concerned with the case, and that only in exceptional circumstances will it be necessary to invoke the additional legal supervision envisaged in some of the proposals for change.

The model of a mental health panel, as put forward by the SAD working group, raised a number of reservations among participants, who saw practical and economic problems in setting up a comprehensive service. However, the potential value of a panel system, with its admirable bringing together of lay and professional viewpoints, was not in doubt and its practicality should be pursued. At the same time, arrangements presently used or proposed in other countries, including protective administration and tutorship, must be examined.

#### 4.10 Recommendations

It seems clear that the care of the elderly with mental disorder should be enhanced by some form of improved legal supervision.

While present legislation in Scotland might be more fully used or might be improved by minor alterations, there is reason to suggest that entirely new legislation is required if the reasonable needs of the elderly are to be met and their welfare safeguarded.

A high quality of supervision, whether involving dementia teams or multi-professional case conferences, is essential but may have the effect of interfering with the freedom of the individual at risk and should, therefore, be covered by appropriate legislation which meets the recommendations of articles 5 and 6 of the European Convention on Human Rights.

A number of innovative measures, including the mental health panel proposed by SAD, deserve further appraisal in every country where legislation affecting the elderly is being reviewed.

#### 5. Could good examples have a multiplier effect in other Member States?

The mental health needs of the elderly constitute an important focus of the intercountry activities on mental health developed by the Regional Office in collaboration with Member States.

An important aspect to be taken into consideration is the development of guidelines at national and international level to cover the rights of those who, by reason of their impaired mental state, might no longer be capable of managing their own personal or financial affairs, or might have to be detained in an institution.

The action taken by the Mental Welfare Commission in raising and discussing these issues seems relevant for other European Member States of the Region which might consider organizing similar meetings on this theme.

It is hoped that the dissemination of the Scottish example to Member States as well as to experts and nongovernmental organizations could stimulate or strengthen the action already being taken to promote the health and wellbeing of the elderly in the European Region.

Annex 1

Working Group on Prevention and Reduction  
of Mental Health Problems in the Elderly

Groningen, 29 April - 3 May 1985

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23 May 1985  
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### SUMMARY REPORT

The aim of the Working Group was to consider the mental health needs of the elderly, on the basis of the available information on psychogeriatric services in Europe and of the aspects of care of the elderly highlighted by the WHO Working Group held in Cork from 3 to 7 October 1983. In particular, the Working Group was asked to examine how mental health problems in the elderly might be prevented or reduced by early intervention or by specific management techniques.

The participants from 15 countries included 16 temporary advisers, 11 representatives from intergovernmental, nongovernmental and national organizations, and representatives from 7 WHO mental health collaborating centres.

#### Discussion

The discussion centred on the following topics:

- the "scenario" approach to health planning that has been developed in the Netherlands and which is based on a study of all the possible independent changes that may occur within a health care system and on the implications of these changes for policy-making;
- the identification of mental health problems by use of the International classification of impairments, disabilities and handicaps, in addition to the more usual International classification of diseases;
- the various approaches adopted by different countries to cope with mental health problems in the elderly;
- the value of quality control in the services provided for old people, to alleviate the hazards of institutional care and, equally important, of community care;
- the functional stages of Alzheimer-type dementia as an example of a more precise assessment of disability than is usually applied.

Certain general issues of importance emerged during the meeting and deserve particular mention.

Any consideration of mental health problems in the elderly must take into account the distinct and different needs of the "younger" elderly and of the older age group (75 years and over) in terms of mental health problems and of demographic trends.

Widespread concern that adequate resources should be allocated to deal with the silent epidemic of dementia should not mean that the other mental health problems affecting old people, depressive illness in particular, are neglected.

Any discussion about the prevention of mental disorders in the elderly must acknowledge the effect of political decisions on key issues such as housing, social services and financial support, and the need for intersectoral cooperation in these areas.

While efforts to improve health care by the year 2000 are praiseworthy, it is evident that measures to improve the mental health status of the elderly may take effect only many years after their implementation. This is particularly the case in the domain of health education and health promotion.

#### Conclusions

Planning. The prevention and improvement of mental ill health among old people must depend on planning, whether this involves the development of educational programmes, the identification of those most at risk, or the appropriate care of those in need. In addition to the established methods of epidemiological research and case-finding, the planning of appropriate facilities and services could be helped if all the possible eventualities were considered, as demonstrated by the "scenario" approach developed in the Netherlands. The methods for identifying impairments, disabilities and handicaps developed in the proposed international classification are another way of evaluating the benefits and effectiveness of different facilities.

Range of services. The services available to the elderly vary considerably from one country to another and even from area to area within a country. This is no bad thing if it allows flexibility in the use of resources and means that facilities are distributed according to the needs of the local population. Nevertheless, a service should always have an adequate range of facilities and genuine coordination to ensure their appropriate use. Furthermore, a placement in one type of facility rather than another should entail no financial hardship to the elderly person or to the care-giver.

In view of the continuing misunderstandings among the participants from their different use of terms for facilities for the elderly, e.g. assessment unit, nursing home, day centre, a more universally agreed nomenclature and glossary should be developed.

Quality control. Services ought to be assessed and supervised and this should hold not only for all institutions but also for community services; it is important to reach international agreement on basic standards of care that are acceptable. These standards will be enforceable only if a government-recognized body and a professional peer group supervise them regularly and if family members, local representatives and the old people themselves participate in the organization of services. A further safeguard could be the requirement that an official advocate should deal with the personal and financial problems of elderly people at risk through mental impairment. The legal safeguards over the involuntary admission and treatment of those suffering from the dementias deserve careful consideration.

Education and training. The prevention and reduction of mental health problems in the elderly depend on an understanding of how loneliness, isolation, bereavement, recent physical or mental ill health, or inappropriate treatment and care, can adversely affect old people. Everyone would gain from being informed about these matters, but it would be particularly relevant to politicians, health professionals and families. For example, families could be helped if they knew more about the likely outcome of psychiatric illness and the support they could receive as the illness progressed.

Recommendations

Local or national level

1. The use of the "scenario" approach in the planning of services should be explored.
2. Mental health services for the elderly should be flexible, comprehensive and effectively coordinated.
3. All those coming into the services should receive a full social and clinical assessment.
4. Ways and means should be examined of developing registers of people at risk, based on risk indicators in the elderly.
5. Improvements should be made to the methods that enable the social and medical services to make contact with elderly people who are at risk but who do not readily identify themselves.
6. Health education and training programmes should be developed for old people, their families and professional workers and emphasize the prevention and reduction of mental ill health. Emphasis should also be placed on the importance of in-service education for professionals working in institutions and for workers in the community, including volunteers.

National and international level

1. A study should be made of the extent to which the descriptions of disabilities in the International classification of impairments, disabilities and handicaps help match specific mental health problems with the appropriate part of a service for old people.
2. All new schemes for care of the elderly with mental disorders should allow for evaluation of their use and outcome.
3. Guidelines should be developed to define and protect the rights of old people who, because of their impaired mental state, may have to be detained in an institution or who may no longer be capable of managing their own affairs.

Annex 2

LIST OF PARTICIPANTS

**NETHERLANDS**

Mr G. Dekker  
 Legal Adviser, Inspectorate for Mental Health

**NORWAY**

Mr J. Hoyersten  
 Clinical pathologist, Institute of Gerontology

**SWITZERLAND**

Dr T.W. Harding  
 Département de la prévoyance sociale et de la santé publique, Institut  
 Universitaire de Médecine Légale, Lausanne

**UNITED KINGDOM**

Mr J. Bailey  
 Director, Scottish Association for Mental Health

Mr D.A. Bennet  
 Assistant Secretary, Social Work Services Group, Scotland

Mr W. Bingley  
 Legal Director, National Association for Mental Health in England and  
 Wales (MIND)

Dr W.D. Boyd  
 Commissioner, Mental Welfare Commission for Scotland

Mr R. Brodie  
 Solicitor to the Secretary of State for Scotland

Dr P.W. Brooks  
 Senior Medical Officer, Scottish Home and Health Department

Dr E.M. Clive  
 Commissioner, Scottish Law Commission

Dr H.C. Fowlie  
 Vice-Chairman, Mental Welfare Commission for Scotland

Dr D. Greaves  
 Centre of Medical Law and Ethics, King's College, University of London

Mrs S. Hornby  
 Legal Adviser, Age Concern England

Ms L. Hunt  
Senior Adviser, Social Work Services Group, Scotland

Dr A. Jacques  
Consultant Psychogeriatrician, Edinburgh

Dr R.A. McCreadie  
Lecturer, Faculty of Law, University of Edinburgh

Mrs C.E. McGregor  
Social Work Officer, Mental Welfare Commission for Scotland

Mr P.C. Millar  
Chairman, Mental Welfare Commission for Scotland

Dr J.A.M. Mitchell  
Chairman, Scottish Action on Dementia

Dr D.I. Nichols  
Senior Principal Legal Officer, Scottish Law Commission

Mrs M. Rasbash  
Chairperson, Alzheimer's Disease Society Scotland

Professor J. Williamson  
Chairman, Age Concern Scotland

UNITED STATES OF AMERICA

Dr R. Westlake  
Associate Medical Director, Butler Hospital, Rhode Island

WHO REGIONAL OFFICE FOR EUROPE

Dr J.G. Sampaio Faria  
Regional Officer for Mental Health