

National Council for the Elderly

PROCEEDINGS OF SEMINAR

DEMENTIA SERVICES: INFORMATION AND DEVELOPMENT

ROYAL MARINE HOTEL, DUN LAOGHAIRE

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NATIONAL COUNCIL FOR THE ELDERLY

The National Council for the Elderly was established in January 1990 in succession to the National Council for the Aged which began in June, 1981. The terms of reference of the Council are:

To advise the Minister for Health on all aspects of ageing and the welfare of the elderly, either on its own initiative or at the request of the Minister, and in particular on

- *measures to promote the health of the elderly,*
- *the implementation of the recommendations of the Report, **The Years Ahead - A Policy for the Elderly**,*
- *methods of ensuring co-ordination between public bodies at national and local level in the planning and provision of services for the elderly,*
- *ways of encouraging greater partnership between statutory and voluntary bodies in providing services for the elderly,*
- *meeting the needs of the most vulnerable elderly,*
- *ways of encouraging positive attitudes to life after 65 years and the process of ageing,*
- *ways of encouraging greater participation by elderly people in the life of the community,*
- *models of good practice in the care of the elderly, and*
- *action, based on research, required to plan and develop services for the elderly*

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IORKVVORI)

In recent years dementia has become more common as increasing numbers of people are reaching advanced old age. The relative absence of services specifically designed to cope with the condition poses problems for sufferers, carers and service providers in Ireland.

On 4th June 1993, the National Council for the Elderly hosted a Seminar on *Dementia Services: Information and Development*, at the Royal Marine Hotel, Dun Laoghaire. It was attended by over 130 policy makers and providers of services for the elderly with an interest in the problems and challenges presented by dementia.

The purpose of the Seminar was to consider a proposal to establish a Dementia Services Information and Development Centre in Ireland which would encourage the development of high quality services for people with dementia and their carers. The response to this proposal was overwhelmingly positive and it was agreed that the National Council for the Elderly should establish a Committee to progress the matter further.

On behalf of the Council I wish to thank the speakers and participants for their contributions to the discussion. I wish also to thank the Council's staff for organising the Seminar and producing this summary of the Seminar proceedings.

Michael White,
Chairman.

OPENING ADDRESS

Mr. Michael White

The Seminar opened with a welcoming address from Mr. Michael White, Chairman of the National Council for the Elderly. He said he was pleased to note the great diversity of people present, including delegates from Scotland and Northern Ireland, and to note that not only were the statutory, voluntary and private sectors well represented, but that all eight health boards were represented also.

He pointed out that the purpose of the Seminar was to explore the merits of establishing a *Dementia Senices Information and Development Centre* in the Republic of Ireland, on the lines of the Dementia Services Development Centre which was established in 1989 at the University of Stirling in Scotland. He said that the Seminar would provide an opportunity to learn of developments in Scotland, and in Northern Ireland where a steering group had been organised to explore the need for and the feasibility of establishing a Centre based on the Scottish model. It would also provide an opportunity to explore the role of information in the understanding and management of dementia in Ireland and to evaluate service provision for dementia sufferers and their carers.

The National Council for the Elderly was pleased to be involved in this project. However, Mr. White said that it was the service providers and policy makers who must decide if the establishment of a Dementia Centre is one of the ways of ensuring that service provision is adequate for this most vulnerable section of the community. In conclusion he said that if it was decided to pursue the idea of establishing a Dementia Centre at the Seminar, it would also be the service providers and policy makers who would ensure that the idea would be implemented successfully.

INTRODUCTION

Dr. Ruth Barrington

Dr. Ruth Barrington introduced the Seminar and acknowledged how pleased the Department of Health were to be associated with the day. She recalled that the first time she had heard the term Dementia Information Centre was during an informal chat (which was sparked by the developments in Scotland) with Mrs. Faith Gibson of the University of Ulster at Coleraine and Mrs. Joan Dixon of the Department of Health and Social Services in Northern Ireland, among others, at a Conference in Co. Down organised by the Carnegie Foundation on the Third Age. It was agreed that it would be a good idea to explore the possibility of an Irish link with the Dementia Services Development Centre in Scotland to promote the interests of people with dementia in this country and provide a source of information and expertise on dementia, of assistance to professionals and carers and indirectly to people suffering from dementia.

Dr. Barrington thanked the National Council for the Elderly, on behalf of the Department of Health, for taking the initiative and presenting an opportunity to discuss the need to develop a Dementia Centre in this country.

She assured the participants that the meeting was very much an exploratory exercise and that nothing had been pre-ordained. People should be free to express their opinions as to whether or not the proposed Centre was the priority for service development for people with dementia. She said that she hoped that at the end of the day some consensus would emerge as to whether this was something which ought to be pursued, and if so, in what manner should it be pursued.

Dr. Barrington concluded by saying that the issue of funding also needed to be explored and a decision reached as to whether or not this idea was something for which funding might be sought.

THE SCOTTISH EXPERIENCE OF ESTABLISHING A DEMENTIA SERVICES DEVELOPMENT CENTRE

Professor Mary Marshall

Professor Mary Marshall said that the prospect of a sister centre in Ireland was an exciting one for the Dementia Services Development Centre in Scotland.

She went on to present the following statistics and historical background to the Dementia Services Development Centre:

- There are 93,000 people with dementia in Scotland, which has a total population of 5 million people.
- A 25% increase is expected in the next 15 years.
- There are possibly 2,000 people with dementia in the 40 - 65 age group, including people with Aids and Down's Syndrome.
- 80% live at home.
- 50% live alone.

The Dementia Services Development Centre was established in Scotland because there was a shortfall in services and there was a need to work very fast to ensure that service provision for people with dementia was adequate to meet increasing need.

In Scotland there is an arrangement of three organisations, known as the Dementia Alliance: (1) Scottish Action on Dementia (2) Alzheimer's Scotland (3) The Dementia Services Development Centre.

Scottish Action on Dementia, established in 1985, is a very successful lobbying and policy body, made up of professionals, voluntary organisations and carers. They lobbied the Scottish Office and, together with other agencies, were successful in convincing them to make dementia the top priority for health services in Scotland for the rest of the century.

Scottish Action on Dementia found they were being asked to provide information, to carry out research and to assist in the development of

services and training, although they were not in a position to do so. However, they produced a policy document which they sent to educational establishments in Scotland requesting them to bid for a Dementia Services Development Centre. The University of Stirling was finally chosen as the location for the Centre and it was established there in 1988 as a charity.

Alzheimer's Scotland takes prime responsibility for the care of the carers.

THE DEMENTIA SERVICES DEVELOPMENT CENTRE

Professor Marshall presented a detailed description of the Scottish Centre which is a resource for staff who plan, manage and provide services for people with dementia and their carers. It targets planners, managers, professionals, committee members and trainers in health boards, local authorities, and in the voluntary and private sectors. It does not deal directly with carers.

A Board of Trustees was established which is made up of three university professors, three representatives from Scottish Action on Dementia and representatives from other key groups in Scotland.

Amongst other things, the location in a university gives status to the Centre and thus to working with people with dementia.

The staff are employed by the university but report quarterly to the Trustees.

The aim of the Centre is *to extend and improve services for people with dementia and carers*. This is a very clear aim and allows the Centre to decline certain requests, e.g., scientific research into the nature of dementia and prevalence surveys.

Although the Centre does not act as a lobbying body it seizes any opportunity to promote services and to demonstrate that working in the field of dementia is the most exciting kind of work that is available.

FUNDING

Raising funds is probably one of its most difficult challenges.

The Centre receives a core grant from the Scottish Office which can never exceed 40% of its budget.

Funding is also secured through secondments and grants from health boards and local authorities, trust funds and income from publications, conferences and consultancy fees.

The 1991/1992 budget was in the region of £215,775.

STAFFING

The Centre has the following staff:

- 1 Director
- 2 Field Workers
- 2 Information Officers (job sharing)
- 1 Training Officer
- 4 Secretaries
- 2 Research Assistants

COMPONENTS OF THE CENTRE

There are four components which are co-ordinated in the overall work of the Centre: Information, Development, Training and Research.

INFORMATION

Information Collection

- Surveys
- Visits to services
- Networking
- Scanning literature

Information Storage

- Two data bases which can be linked to other universities and contain (1) all published material and (2) specialist services.
- Card index of current research which will be computerised shortly.
- Library

Information Dissemination

- Telephone
- Writing
- Calling to the Centre
Approximately 60 requests per month.

Conferences and Workshops

Conferences and workshops are held twice monthly, and the topics are chosen in response to requests for help. The Centre has a mailing list of 1,500 people who are notified about conferences and publications.

Publications

Approximately two publications are produced per month. Again, the titles reflect requests for help received by the Centre.

DEVELOPMENT

Development staff work in the field most of the time, meeting people who are providing a service and helping them to improve this service by providing models of good practice, contacts, advice, ideas and support.

Consultancy: Fees are in the region of £300 per day although there is no charge for sessions of less than two hours. However, there is a policy that cost should never be a barrier to providing help.

Special commissions are undertaken, such as setting up a mental health development team for a health board, giving talks and contributing to books and articles.

TRAINING

As the Centre receives a training grant for only one person, it has begun with training managers, planners and training officers whose expertise can be passed on to other staff.

Training materials and information are also produced.

RESEARCH

The Centre carries out increasing amounts of research and this is encouraged by its location in a university.

It specialises in the evaluation of services. This kind of research plays an important part in promoting better practice because it provides evidence on which models of good practice and services work best.

THE NORTHERN IRELAND EFFORTS TO ESTABLISH A DEMENTIA SERVICES DEVELOPMENT CENTRE

Mrs Faith Gibson

Faith Gibson brought greetings from the Steering Group which was established in Northern Ireland in November 1992 to pursue the questions of the necessity and feasibility of establishing a Centre in Northern Ireland to progress the issue of dementia in a number of ways.

In her address she described the origin of the Steering Group, what it has done to date and where it hopes to go in the future.

Influenced by the Scottish Centre and the forthcoming *European Year of Older People and Solidarity between Generations* in 1993, she and others took the opportunity to interest the Department of Health and Social Services in the idea of trying to move dementia up the agenda. The establishment of a Centre, akin to the one at the University of Stirling, was seen as one way of doing this.

The Department of Health and Social Services agreed to convene a small working group to further develop this idea. Then in November 1992 they hosted a meeting similar to the Dublin Seminar, which was a large and representative gathering and was addressed by Professor Mary Marshall.

At that meeting people were asked to volunteer to become part of a working group and more than sufficient volunteers agreed to assist. By late November 1992, a Steering Group had been formed. It is chaired by Faith Gibson and is representative of all four Health and Social Services Boards and all major professions with a stake in dementia care: medical, nursing and social work. It is also representative of all service providers: statutory, voluntary and private, as well as hospitals, nursing homes, residential homes, day care and services which are provided at home. This Steering Group has met six times in the period November 1992 to May 1993 and has received some financial support from a range of sources.

The task of the group is to explore the need for and the feasibility of establishing a Dementia Services Development Centre.

The group began by clarifying the kinds of functions such a Centre might fulfil: information, consultancy, advice, evaluative research and training. It confirmed that these functions were not already being effectively carried out by existing organisations.

In order to gather some evidence on the need for a Centre, a postal questionnaire was administered to 400 professionals representing the major professions engaged in dementia care. A separate survey of 100 carers was also carried out which asked carers about their perception of the competence and understanding of the professionals they had encountered. The findings have yet to be analysed.

The survey of the professionals indicated that they recognise the shortcomings in their knowledge, access to contemporary research findings and interdisciplinary training opportunities, and the need for an effective forum to share their ideas and to make plans.

All the professionals with the exception of the consultant geriatricians and the psychogeriatricians, felt that their basic training did not adequately equip them for their present work in the field of dementia services and that opportunities for training, for access to research and adequate support are severely limited.

For information on dementia these professionals rely heavily on limited reading and on colleagues whom they acknowledge may be equally ill-informed. They believe that dementia services are neither adequately monitored nor planned with due attention to relevant contemporary international and independent research.

With the exception of a small number of GPs who displayed some indifference, the professionals strongly supported the proposal to establish a dementia Centre.

Having determined the need for a service, from a number of sources, the Steering Group considered the feasibility of seven different options for developing a Centre in Northern Ireland.

1. The first option, to take no initiative, was seen as unacceptable given the findings of the surveys.
2. The idea of establishing a Centre in an existing statutory organisation was also ruled out because there would be certain geographical barriers to access. Location in a single Health and Social Services Board might dissuade or preclude some people from using it. It might be seen as partial and lacking independence.

3. Location in an existing voluntary organisation was considered to be an unsuitable compromise for some of the same reasons but also because it would run the risk of subverting their already heavy workload at a time when funding was uncertain. This option was also seen as unfeasible because the Centre might be overly identified with a single organisation. Research expertise and access to information would have to be purchased and none of the existing voluntary organisations were making a bid for the Centre.
4. The fourth option was to persuade the Stirling Centre to extend its services to Northern Ireland. Although this option has not yet been ruled out, some disincentives were identified. It would entail the purchasing of services from Stirling, it would restrict easy access and a wide uptake of services, and it would mean that Stirling would have to employ some staff and locate them in Northern Ireland where they would be divorced from the support from their home base. Finally, this option could make training more expensive and curtail the training opportunities which could be developed locally.
5. The group also considered the option that the Centre could be located in an existing privately funded organisation. This was ruled out on the basis that no existing organisation spanned the range of expertise which is necessary. There would be problems of acceptability and accessibility and there would be difficulty in resourcing such a choice.
6. Although the possibility of establishing a new, free standing voluntary organisation with a charitable charter was considered, it was felt that in Northern Ireland at present this would be a difficult idea to sell and to fund, and it would also require access to library, computing, information handling and research expertise.
7. The idea of a university based Centre, like the one in Stirling, which would provide ready access to a range of services and expertise, was seen as the most favourable option. It was felt that this option would be more cost effective than any of the other alternatives.

Having examined the feasibility of several options, the group requested a meeting with the Department of Health and Social Services to determine the Department's interest in providing core funding for a start-up period which might make it possible for a Centre to approach other sources of funding in order to become financially viable.

Although such a commitment was not given, the group received sufficient encouragement to move on to the next stage.

The Steering Group have recently written to the Department of Health and Social Services requesting them to commission *bona fide* management consultants to undertake an option appraisal (examining all of the identified options) which will focus on costings, forecasts of uptake and how the two Northern Ireland Universities might respond should they be invited to tender for a Centre. It is hoped that the option appraisal report will be ready by the end of September 1993 so that the Steering Group can report to the Department of Health and Social Services by late October 1993 with a series of recommendations.

Faith Gibson concluded her presentation by saying that a Dementia Services Development Centre for Northern Ireland would make a significant contribution to eliminating the worst practice, to improving the mediocre and to turning the reasonably good into excellence.

THE NEED FOR ESTABLISHING A DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE IN IRELAND

Dr Margo Wrigley

Dr. Margo Wrigley began by saying that in her view dementia is a condition which is dealt with poorly in the Republic of Ireland and that her presentation would concentrate mainly on this problem. She went on to address the following issues:

- The attitude of people in general to dementia in Ireland
- How we have dealt with the problem historically
- The response to dementia of people who work in the health and welfare services
- Government policy
- Her own personal experience of working in Dublin with people with dementia and their carers

THE ATTITUDE OF PEOPLE IN GENERAL TO DEMENTIA IN IRELAND

People in general have considerable fears about dementia which are based on the misconception and widespread myth that people with dementia are in some way deranged and violent and invariably act in this way. This is in fact far from the truth and when this sort of behaviour does exist there is generally an underlying reason which can be dealt with if the appropriate help is available. Such misconceptions are based on ignorance about dementia, which leads to fear and to denial and rejection of the problem. This is society's way of dealing with the anxiety of impending old age and possible senility.

This attitude means that the public do not place much pressure on the Government to develop services for people with dementia, despite a general awareness that services are poor. There is a need, therefore, for considerable education of the public about dementia : exactly what it is and how appropriate services, which are not necessarily expensive,

can ease the problems that are caused by dementia and help relatives who are shouldering the burden of care.

HOW WE HAVE DEALT WITH THE PROBLEM OF DEMENTIA HISTORICALLY

In the past, society's attitude to dementia was reflected in its response to the problems associated with this illness. In other words, the problems were ignored until the relatives were at breaking point or the sufferer was at such enormous risk that the problems could be ignored no longer. At this stage crisis institutionalisation occurred, using whatever large institution was available locally. This was generally the local asylum which was not ideally suited to the care of people with dementia. However, in recent years the increasing numbers of people surviving into old age, when they are more likely to suffer from dementia, has meant that the large institutions are no longer able to cope with the increasing numbers of people with dementia.

THE RESPONSE TO DEMENTIA OF PEOPLE WHO WORK IN THE HEALTH AND WELFARE SERVICES

People working in the health and welfare services, like the general public, experience the fear of their own impending old age and possible senility, which in turn can lead to a denial of the problem. However, they also experience a very real fear that if they show any interest in dementia, they will be inundated with requests for help and overwhelmed by the problem. It is often thought that the problem of dementia is uncontrollable and unmanageable, which is untrue.

Because of these fears, little attempt was made to organise proper services for dementia sufferers, and crisis institutionalisation in asylums continued. Now, with the change in the mental health services, large asylums are no longer available and the result has been that people with dementia are being increasingly admitted to acute hospitals, at a crisis stage and are thereby contributing to the problem of blocked beds in acute hospitals. The opening of more acute hospital beds or the intermittent buying of nursing home places will not reduce the problem. A proper range of community support services and residential places are needed for people with dementia.

GOVERNMENT POLICY

The Years Ahead ...A Policy for the Elderly which was published five years ago and is now accepted Government policy, devotes a chapter to dementia. This chapter acknowledges the dearth of services, emphasises

the role of carers, particularly family carers, and the need for a continuum of care.

It gives the Belfast model of services for elderly people with dementia as an example of good practice. This model illustrates the importance of social services, which would be equivalent to our community care programme, medical services for the elderly and psychiatry of old age, working together to ensure that the full range of flexible community support, residential care and acute medical and psychiatric services are available to dementia sufferers and their carers.

Regretfully the impetus from Government to develop these services has so far been lacking, particularly in terms of adequate and specific funding for dementia. This lack reflects, in part, public attitudes and an unwillingness to pressurise the Government to develop the services that are needed.

DR. WRIGLEY'S PERSONAL EXPERIENCE OF WORKING WITH PEOPLE WITH DEMENTIA AND THEIR CARERS IN DUBLIN

Dr Wrigley has worked in the psychiatry of old age in North Dublin for the past four years and about half of the people referred to her service suffer from dementia. She was initially struck by the reluctance, until the last year or two, to discuss or tackle the problem at all. Because of this, available help on the ground has been very difficult to arrange even if it is urgently required. This has been especially striking when dementia sufferers require residential care and each case requires that a time consuming individual arrangement has to be made to solve the problem.

There is also a lack of day care centres for people with dementia in the North Dublin area, although the situation has been improved in recent years since the Alzheimer Society of Ireland opened their day care centre. Some of the local day centres are also considering trying to look after people with dementia and while this will certainly make a difference, there is still a considerable shortage given the number of places which will be needed.

Day hospitals are available in North Dublin in both medicine for the elderly and the psychiatry of old age services, but they would soon cease to function as therapeutic units if, by default, they had to provide daycare for dementia sufferers, who were not specifically in need of medical or psychiatric treatment or monitoring.

Dr. Wrigley feels that, in Ireland, we are very fortunate that so many people with dementia have involved and caring families. However, she

said that regrettably these families do not get the support that they deserve in terms of home, day and respite care and that this is something which needs to be addressed.

She went on to say that despite the fact that much of her presentation had painted a pessimistic picture, things have improved in the last couple of years. We are beginning to hear about dementia and especially Alzheimer's disease, thanks to the efforts of the Alzheimer Society of Ireland.

Since *The Years Ahead* report was published some of its recommendations have been implemented, most notably care teams for the elderly have been set up in some community care areas. As a result, dementia regularly features on the agenda at community care level and new initiatives are being planned.

Medicine for the elderly has also developed in the last few years and the psychiatry of old age has made a start albeit a rather small one. Two psychiatry of old age services are in operation and it is hoped more will follow.

Dr Wrigley stressed that, in her experience, GPs have been very welcoming of the North Dublin service and have worked very closely with it.

CONCLUSION

Dr Wrigley concluded by expressing the view that given the recent positive changes in services for dementia sufferers, now is an opportune time to consider setting up a Dementia Centre to support further developments. She felt that dementia is a poorly understood condition in the Republic of Ireland and is also poorly dealt with. Because of this there is unnecessary suffering for people with dementia and their carers. This also causes inefficiencies in other parts of the health services, particularly the acute hospitals which by default have to make up for the deficiencies in services for people with dementia.

There is now a willingness to face the problem of dementia and a Centre could play a most useful role in providing information and ensuring that good quality services are developed.

THE POSSIBLE ROLE AND FUNCTIONS OF A DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE IN IRELAND

Dr. Des O'Neill

In his presentation Dr. Des O'Neill highlighted the fact that approaches to dementia differ in various countries and that, even within countries, carers and various professionals often have different perspectives on dementia. He pointed out the importance of taking these points into consideration when looking at the possibility of a Dementia Services Information and Development Centre for Ireland. He also said that it would be important to look at the strengths and weaknesses of the Irish system in relation to establishing such a Centre.

The British Society of Gerontology has a strong social gerontological slant but the Irish Society of Gerontology, while it is multi-disciplinary, has a strong medical and psychiatric orientation because a lot of the basic research and interest has started from a medical viewpoint. Dr. O'Neill pointed out that he was delighted to see the cross-section of professionals at the Seminar because it is important that professionals get together to share their expertise.

Although there is a degree of ignorance, not only among the public but also among health care professionals, about dementia, this is changing and people are becoming more aware and knowledgeable about the subject. Dr. O'Neill gave the example of when the memory clinic in St. James's Hospital was started in the mid '80s and he had to explain to people what Alzheimer's disease was. When he left three years later, the relatives were asking if the patient had Alzheimer's disease. He also pointed out that in the United Kingdom people with dementia were being referred by GPs at much earlier stages over a period of a few years once a centre of excellence had been established.

In the United States, THA (a drug that may have some small effect on Alzheimer's disease in a small minority of patients) has now got a licence, largely through the lobbying of the Alzheimer Society and other pressure groups. It will get a licence in Europe too, and when it does there will be increasing emphasis on dementia.

In the Republic of Ireland, services for people with dementia and their carers are less developed than in the United Kingdom, particularly in

Scotland and Northern Ireland, where there is more funding per head of population for health services. Ireland, therefore, is starting in a very disadvantaged position from a material point of view.

However, in Ireland, like in other countries, informal care plays a very important role in service provision for dementia sufferers and a lot of knowledge comes from listening to the experiences of carers. Dr. O'Neill expressed the view that the book *The 36 Hour Day*,¹ which highlights carers' experiences, should be required reading for every health care professional.

There is also a caring ethic, good quality personnel, tremendous enthusiasm and goodwill, and a desire to get things done in Ireland despite the fact that services are underdeveloped. Dr. O'Neill pointed out that one of the reasons why the Scottish development was so successful was because it is a relatively small country where professionals have more opportunities to meet their colleagues. This should also be the case in Ireland.

The specialist care provided for people with dementia and their carers in Ireland, like in the United States, draws on a wide range of influences including geriatricians, psychiatrists, neurologists and psychogeriatricians. The involvement of geriatricians in dementia care and assessment is common in Ireland, while in the United Kingdom it is mostly psychogeriatricians among others who care for dementia sufferers and there is a psychogeriatric department in virtually every health authority. These different methods of caring for people provide a richness in the Irish system but we need more feedback about how this system is working. There is a need for better communication between these different professionals and a Dementia Centre would provide a clearing house which could help to co-ordinate and evaluate this style of assessment, referral and management and provide a forum for discussion.

The voluntary sector is so much stronger in Ireland than in the United Kingdom and this too must be borne in mind when considering the role and functions of a Dementia Centre.

Dr. O'Neill went on to stress how important it is that services provided for people with dementia relate to their actual needs. He gave the

¹ Mace, N.L. and Rabins, P.V. (1981), *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses and Memory Loss in Later Life*, The John Hopkins University Press, Baltimore.

Mace, N.L. and Rabins, P.V. with Castleton. B.A., Cloke, C. and McEwen, (1985), *The 36-Hour Day: Caring at Home for Confused Elderly People*, Hodder and Stoughton in conjunction with Age Concern, London.

example of a GP carer pack which had a mental test score which many people believed was inappropriate for use in general practice. He expressed the view that a Dementia Centre could provide a forum for discussion on matters like this and ensure that services relate to needs.

The establishment of a Centre could provide an opportunity to push for services which are best tailored to Ireland, although, like in Scotland, it would be important to limit the scope of the services provided by the Centre.

Dr. O'Neill felt that a helpline is a much needed and worthwhile service because carers and people with dementia have nowhere to get information. While providing a very important service for individuals, a helpline could also provide ideas for service planning, information on local needs, feedback and information from health care professionals, as well as identify gaps in service provision. In this way, the helpline which could be run by trained volunteers, could act as a central network for information.

A university base would help to raise the profile of a Centre and provide the technical support, enthusiasm and vigour which are so important.

Although training would be an important function of the Centre, Dr. O'Neill felt that it should play a role in the co-ordination of training rather than have a large team of trainers.

Our links, not only with Scotland and Northern Ireland but also with Australia and North America, should be a useful information source and we should take advantage of these rather than duplicate the work of other Centres. Dr. O'Neill gave examples of Centres in North America which provide services somewhat akin to the Scottish Centre and whose experience of community service deficiencies and mixed service provision may in many ways be very relevant for us. These Centres are situated at the National Institute for Health, the University of Kentucky, the Texas Tech University and the University of British Columbia. He went on to say that if we get the right answer to our problems we could perhaps sell our services to other countries.

A good data base which is linked with centres in Scotland, America and other countries as well as with Alzheimer's Disease International would be very useful.

The Centre could provide lists of health care professionals and resources as well as information to be used by people carrying out

research and service planners who might otherwise feel they are working in a vacuum and have nowhere to turn to for information.

Another function of the Centre could be to organise and network the experts and to set standards of care.

In order to avoid the duplication of services it is important that the Alzheimer Society of Ireland continues as the lobbying group while the Centre should provide an information service and ideas.

In conclusion, Dr. O'Neill expressed the view that a Dementia Services Information and Development Centre would be a critical service for Ireland, but that we should avoid duplication and begin with a Centre which is as compact as possible. He stressed the importance of linkage with an academic institution and the fact that the establishment of a Centre in a Department of an academic institution would benefit the Department as well as strengthen the whole area of dementia, as it has done in Scotland. Although he did not suggest a location, he did point out that it would be important that the main person(s) running the Centre should have a particular interest in dementia and some expertise in the area. He/she should also have a mission to undertake research, to find out what the problems are, and have a desire to get things done.

WORKSHOP CONCLUSIONS

DEMENTIA SERVICES: INFORMATION AND DEVELOPMENT

In the afternoon, the participants broke into four workshops to address the following questions:

1. Do we need a Dementia Services Information and Development Centre in this country?
2. What information services might such a Centre usefully provide?
3. What dementia services need to be developed and how could the proposed Centre assist in their development?
4. How should the proposed Centre be established?

Each workshop Rapporteur presented the conclusions reached in their workshop in the final summing up session. The conclusions were as follows:

- All four groups expressed the view that there is a definite need for a Dementia Centre in Ireland, but that perhaps we should start in a more modest way than in Scotland.
- It was proposed that the Centre could:
 - provide a data base on services and other information which is linked to all health boards
 - give personal advice (perhaps in the form of a helpline)
 - improve communication
 - identify service gaps
 - co-ordinate services
 - provide staff support

- improve the status of those working with people with dementia
 - develop a common language to be used with regard to dementia
 - organise training and information on training
 - record completed and ongoing research
 - pilot research projects and carry out evaluation
 - increase public awareness
 - provide models of good practice
 - provide information on planning
- It was suggested that a questionnaire be administered to sample informed opinion among carers and professionals on the services such a Centre could provide which would be of use to them. (Similar to the one administered in Northern Ireland).
 - Although it was proposed that the Centre could meet the needs of professionals, policy makers, health service planners, health service managers and carers, there was some indecision as to whether one national Centre could provide services for carers at local level in addition to centralised services for professionals, etc. (The Scottish Centre does not deal directly with carers).
 - It was also pointed out that the services provided by the Centre should complement rather than overlap with those provided by other agencies such as the Alzheimer Society of Ireland.
 - It was agreed that the Alzheimer Society would be in a better position than the Centre to organise a helpline, which would not only provide information but also collect information and in this way duplication of services could be avoided.
 - Despite the comparative shortfall in dementia services in the Republic compared to Northern Ireland and to Scotland, it was concluded that the Centre should be given priority because it would promote the development of services.

- The Centre could also help to ensure that concern for the elderly does not slip off the political agenda and lose momentum. It could also give impetus to the implementation of the recommendations of the *Years Ahead* Report and the Green Paper on Mental Health, regarding dementia.
- Legislation on dealing with people with dementia could be addressed.
- Although it was agreed that major investment is needed in all services, the following ones particularly need to be developed:
 - 24 hour a day, 7 days a week community services
 - specialised day centres for people with severe dementia and transport to the centres
 - day hospitals
 - respite care/day sitting services
 - diagnostic and assessment services at community level
 - earlier intervention
- The importance of a North/South link was agreed by all four groups. However it was felt that a single Centre for the North and the South would not be the most feasible model because of different health services in both parts of the country. It was suggested that a feasibility study could be carried out to consider the possibility of a joint venture with Northern Ireland. Data base linkage on information that is common would be important between the Centre in the Republic and the one in Northern Ireland, as well as between Scotland and other countries.
- One group felt that we should not automatically follow the Scottish model but that we should get information on the American, Australian and other approaches and carry out a feasibility study on models for a Centre.
- With regard to funding, it was agreed that the figure for funding discussed by Professor Mary Marshall for the Scottish Centre (i.e., £200,000 approx), was extremely good value. A similar sum divided between the eight health boards in Ireland would not be considered as a very large sum. As it is unlikely that the

Centre will be self-financing, there were strong arguments for Government support.

- It was agreed that it would be important to take advantage of the *European Year of Older People and Solidarity between Generations* to progress the establishment of the Centre.
- With regard to location, there was general support for linking the Centre with an academic institution or an institution with academic links and for inviting various institutions to tender for it.
- It would be important that the Centre be multi-disciplinary, with high profile trustees to give it status and acceptability.
- It was agreed that a task group should be set up to examine how the Centre should be established, and that those who were interested in working in such a group should give their names to the National Council for the Elderly, who would then make the necessary arrangements to progress the matter.

SUMMING UP

Professor Davis Coakley

In his role as Chairperson for the final session of the Seminar, Professor Davis Coakley highlighted the most important conclusions from the Workshops.

He said that there was a feeling that there was a great need for a Centre even if we start on a modest basis.

A Centre seems to be needed for several reasons including communication, information, identifying service gaps and co-ordination of services.

It could also act as a focus for research and have an educational dimension.

Such a Centre should complement rather than overlap with other services such as the excellent service provided by the Alzheimer Society of Ireland.

There were no ideas about the location of a Centre but there seemed to be general support for linking it with some academic institution or an institution with academic links.

Professor Coakley felt that this was an opportunity for some co-operation between the North and the South of Ireland. Even though services are different in these parts of the country, we should take advantage of the experience they have in the North of developing their services. The idea of some link between North and South seemed to go right through all four groups.

Although the issue of funding could not be solved at the Seminar there did seem to be very strong arguments for a Government role. Professor Coakley agreed with the idea of taking advantage of the *European Year of Older People and Solidarity between Generations* and said that this is a good time to move on an issue like this.

He went on to suggest that as it seemed to be universally felt that there is a need for a Centre and as several of the groups suggested setting up a Task Group, people who felt they would have the time and the dedication

to work in such a Group, would give their name to Mr. Bob Carroll of the National Council for the Elderly, who would look to ways of progressing the project.

CLOSING ADDRESS

Mr. Kieran Hickey

The day ended with a closing address from Mr. Kieran Hickey, Chief Executive Officer of the Eastern Health Board. He said that he was pleased that the Seminar had taken place because it provided an opportunity for many involved and committed people, representing various strands of the health services, to focus on the subject of dementia. He felt that we have tended to shy away from dementia because it has always created difficulties in terms of understanding.

He commended the Alzheimer Society of Ireland for the work they are doing and for having generated a greater confidence in people who are dealing with the problem of dementia.

He went on to say that one of the major challenges for our health care system, with its three programmes, is to ensure that there is a co-ordinated approach and that there is an ability to decide where a particular individual case fits at any one time. A national Dementia Centre, or a Centre of excellence like the Scottish one, could educate and provide information on good practice. However, he expressed some doubt as to whether one national Centre could provide information for individuals at a local level.

He referred to a survey of elderly people with dementia who were causing management problems in the Eastern Health Board area. This survey, which was carried out by the Co-ordinators of Services for the Elderly, concluded that there were about 600 such people in the Eastern Health Board, i.e., 0.5% of the Eastern Health Board elderly population. Mr. Hickey expressed the view that this represented a reasonably manageable figure. The main conclusions of the survey were that long stay care needs to be enhanced, as do day care services, day hospital services, respite care and sitting services, although it is a question of finding the resources to do so.

Mr. Hickey said that since health care provision for the elderly is well represented on the political and Department of Health agendas, the health boards have been able to move in this area in recent years. He expressed his appreciation to officials of the Department of Health for their commitment following the publication of *The Years Ahead* report.

Although there has been some earmarked funding for services for the elderly generally, this has slipped off the agenda somewhat in the last twelve months, with the focus being solely on the nursing home service. Mr. Hickey felt that a national Centre would help to ensure that more resources will be earmarked for dementia sufferers and their carers, keeping dementia high on the health board agendas.

The National Council for the Elderly has already successfully demonstrated how, through research and publications, attention has been drawn to the needs of the elderly. In a similar way, a national Centre could ensure that the problem of dementia is given the attention it needs. He suggested that the establishment of such a Centre under the general auspices of the National Council for the Elderly would be a natural extension of its functions.

Although a national Centre could provide an information service, Mr. Hickey felt that a 24 hour helpline for individual carers would be something that health boards could address, perhaps in consultation with the Alzheimer Society of Ireland.

He said that he would be in favour of a Dementia Centre which would carry out the range of functions mentioned in the discussions, namely, information, research, best practice and keeping dementia to the forefront of public attention.

It would be important that the Centre would interact with the media to ensure that dementia is given public attention and political priority, and receives the funding it requires. After all, it is the availability of funding which will decide what can and cannot be done at the end of the day.

Mr. Hickey went on to say that the health boards are trying to develop a community based approach to service provision while providing for the short stay and long stay institutional care of the elderly in this context. They are also trying to develop greater co-ordination between different professionals. He felt that they are beginning to succeed in both these areas although there is still a long way to go. In this context, he was delighted to see so many Co-ordinators of Services for the Elderly in attendance at the Seminar.

Mr. Hickey concluded his address by suggesting that the National Council for the Elderly would take primary responsibility for advising on the establishment of a national Dementia Centre, with the support of relevant agencies, such as The Mercer's Institute and the health boards, among others. He welcomed the fact that a day had been spent focusing on a problem which is one of the more difficult ones that we have to address. The establishment of a Dementia Centre could help to ensure that we continue to do so.

NOTES ON CONTRIBUTORS

Dr. Ruth Harrington

Dr. Ruth Barrington is Principal Officer in the Department of Health with responsibility for services for the elderly as part of her brief. She was Secretary to the Working Party on Services for the Elderly which produced *The Years Ahead ...A Policy for the Elderly* in 1988. She is also the author of *Health, Medicine and Politics in Ireland 1900 - 1970* (1987).

Professor Davis Coakley

Professor Davis Coakley is Director of Mercer's Institute for Research on Ageing based at St. James's Hospital and Trinity College Dublin. He has recently been appointed Dean of the Health Sciences Faculty in Trinity College, and is Professor of Geriatric Medicine at Trinity College. Professor Coakley is also Consultant Physician in Geriatric Medicine at St. James's Hospital.

Mrs. Faith Gibson

Mrs. Faith Gibson is a Reader in the Department of Applied Social Studies at the University of Ulster at Coleraine. She is also Chairperson of a Steering Group of professionals which was established in 1992 to explore the need for and the feasibility of establishing a Dementia Centre in Northern Ireland. Mrs. Gibson is a member of the National Council for the Elderly.

Mr. Kieran Hickey

Mr. Kieran Hickey is the Chief Executive Officer of the Eastern Health Board.

Professor Mary Marshall

Professor Mary Marshall is Director of the Dementia Services Development Centre at the University of Stirling in Scotland. She was formerly a Lecturer in Applied Social Studies at Liverpool University and Director of Age Concern, Scotland. She has published various

books and articles on the care of the elderly including *Going Home, The Care of Elderly People After Discharge from Hospital* (1975) and *New Services for Older People* (1983).

Dr. Des O'Neill

Dr. Des O'Neill has recently returned to Ireland from the United Kingdom to take up his appointment as Consultant Physician in the Department of Medicine for the Elderly at the Meath and St. James's Hospitals, Dublin. He is also a Director of the Alzheimer Society of Ireland.

Mr. Michael White

Mr. Michael White was appointed Chairman of the National Council for the Elderly in 1993 having been appointed to the first Council in 1981. He has recently been appointed by the Tánaiste to the National Economic and Social Forum.

Dr. Margo Wrigley

Dr. Margo Wrigley is a Consultant Psychiatrist specialising in the Psychiatry of Old Age. She holds a joint appointment with the Eastern Health Board, St. Vincent's Hospital, Fairview and the Mater Hospital. She also provides a community-oriented psychiatric service specifically for older people in North Dublin which is organised from James Connolly Memorial Hospital, Blanchardstown.

NATIONAL COUNCIL FOR THE ELDERLY PUBLICATIONS

1. *Day Hospital Care*, April 1982
2. *Retirement: A General Review*, December 1982
3. *First Annual Report*, December 1982
4. *Community Services for the Elderly*, September 1983
5. *Retirement Age: Fixed or Flexible* (Seminar Proceedings), October 1983
6. *The World of the Elderly: The Rural Experience*, May 1984
7. *Incomes of the Elderly in Ireland: And an Analysis of the State's Contribution*, May 1984
8. *Report on its Three Year Term of Office*, June 1984
9. *Home from Home? Report on Boarding Out Schemes for Older People in Ireland*, November 1985
10. *Housing of the Elderly in Ireland*, December 1985
11. *Institutional Care of the Elderly in Ireland*, December 1985
12. *This is Our World: Perspectives of Some Elderly People on Life in Suburban Dublin*, September 1986
13. *Nursing Homes in the Republic of Ireland: A Study of the Private and Voluntary Sector*, September 1986
14. *"It's Our Home": The Quality of Life in Private and Voluntary Nursing Homes in Ireland*, September 1986
15. *The Elderly in the Community: Transport and Access to Services in Rural Areas*, September 1986
16. *Attitudes of Young People to Ageing and the Elderly*, Second Edition 1992.
17. *Choices in Community Care: Day Centres for the Elderly in the Eastern Health Board*, September 1987
18. *Caring for the Elderly. Part I. A Study of Carers at Home and in the Community*, June 1988
19. *Caring for the Elderly, Part II. The Caring Process: A Study of Carers in the Home*, November 1988
20. *Sheltered Housing in Ireland: Its Role and Contribution in the Care of the Elderly*, May 1989
21. *Report on its Second Term of Office*, May 1989
22. *The Role and Future Development of Nursing Homes in Ireland*, September 1991.
- 23(a) *Co-ordinating Services for the Elderly at the Local Level: Swimming Against the Tide, A Report on Two Pilot Projects*, September 1992.
- 23(b) *Co-ordinating Services for the Elderly at the Local Level: Swimming Against the Tide, Summary of an Evaluation Report on Two Pilot Projects*, September 1992.
24. *The Impact of Social and Economic Policies on Older People in Ireland*, January 1993.
25. *Voluntary-Statutory Partnership in Community Care of the Elderly*, January 1993.
26. *Measures to Promote Health and Autonomy for Older People: A Position Paper*, August 1993.
27. *Co-ordination of Services for the Elderly at the Local Level*, (Proceedings of Seminar, November 1992) September 1993.
28. *Voluntary-Statutory Partnership in Community Care of the Elderly*, (Proceedings of Seminar, February 1993) September 1993.
29. *Dementia Services Information and Development*, (Proceedings of Seminar, June 1993) September 1993.
30. *Bearing Fruit*, A Manual for Primary Schools, September 1993.
31. *In Due Season*, A Manual for Post Primary Schools, September 1993.

National Council for the Elderly Fact Sheets

Fact Sheet 1	Caring for the Elderly at Home
Fact Sheet 2	Carers You Matter Too!
Fact Sheet 3	Ageing in Ireland: Some Basic Facts
Fact Sheet 4	Voluntary Sector Services in the Community

