An Action Plan for Dementia
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As Chairperson of the National Council on Ageing and Older People, it gives me great pleasure to introduce this *Action Plan for Dementia.*

Previous publications by the Council have pointed to the need for significant progress in the care of older Irish people with dementia. In this light, the former Minister for Health requested the National Council on Ageing and Older People to consider ways in which services for people with dementia and their carers might be improved. This report, a major piece of work developed in consultation with a wide variety of bodies from the statutory, voluntary and private sectors, is the outcome of that request.
The *Action Plan* takes as its guiding principle the recognition of the individuality of the person with dementia and of his or her individual needs. This principle has informed and influenced the development of the plan. The needs and uniqueness of the person with dementia must be paramount when we talk of care and service provision.

Action on the treatment of dementia can be delayed no longer. Given the increasing proportion of older people in the population and the higher prevalence of dementia in older age groups, action is needed now. This plan should serve as a model of best practice for the provision and planning of services to meet the individual needs of people with dementia and their carers.

On behalf of the Council I would like to thank the authors of the report, Dr Eamon O’Shea and Ms Siobhan O’Reilly. Thanks are also due to all those who gave of their time to the authors in the consultative process.

I would also like to thank Mr Christopher Domegan and his successor, Dr Margo Wrigley, who chaired the Council Committee which oversaw the preparation of the *Action Plan* in a consultative capacity. Our thanks go to all the members of the Consultative Committee for their guidance and advice. The members were Ms Winifred Bligh, Ms Janet Convery, Dr Murna Downs, Ms Mary Drury, Mr Martin Duffy, Ms Margaret Geary, Mr Frank Goodwin, Cllr Tim Leddin, Dr Aidan Meade, Dr John Murphy, Dr Des O’Neill and Sr Mary Threadgold.

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Dr Michael Loftus
*Chairperson, National Council on Ageing and Older People*
May, 1999
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Executive Summary

Introduction

Dementia as a disability is characterised by the following characteristics: impaired memory, impaired ability to learn, impaired ability to reason, and high levels of stress. The complexity and range of issues involved in the management of dementia emphasise the need for the development of co-ordinated, multi-layered, and well resourced services that are responsive to the individual needs of people with dementia and their carers. People with dementia are a heterogeneous group, which means that there is no single solution to the problem of dementia. An understanding of how the dementia population impacts on the care system is an essential part of the planning process. Equally, the level and quality of support provided to people with cognitive impairment will affect the degree and nature of the disability that results from that impairment.

The effective management of dementia in Ireland necessitates the development of an action plan, incorporating the viewpoints of all major stakeholders. The plan emphasises the uniqueness of the person with dementia. It places the individual with dementia at the centre of the planning process and goes beyond a neuropathological approach to understanding dementia to explore the concept of personhood in dementia within the framework of what Kitwood (1997) calls the ‘new culture of dementia’. The plan outlines the approach to developing available, accessible and high quality services given existing resources and the public expenditure constraints that are likely to continue into the future. The need for a continuum of services is recognised and incorporated into the plan. Financing issues are explicitly considered along with new ways of funding and providing social care services for people with dementia and their carers. The intention is that the plan will serve as a model of best practice, which can guide policy-makers and others involved in planning service provision, and support the providers of local and flexible services for people with dementia.
The dementia population

Estimates by Lawlor et al, (1994) suggests that there are just over 22,000 people with dementia living in the community in Ireland. The number of people with dementia in long-stay care in Ireland varies between 3,755 and 7,380, with the higher figure likely to be the more accurate indicator of prevalence in this setting. The number of people with dementia in psychiatric hospitals is estimated at just over 560 people (Moran and Walsh, 1992). Estimates of the number of people with dementia in acute care hospitals are not available for Ireland, but estimates from one health board suggests that 18 per cent of acute medical beds are occupied by people with significant cognitive impairment (Clinch and Hickey, 1992). The number of people with dementia estimated from the aggregation of prevalence data from Irish sources corresponds closely to the numbers generated by the application of EURODEM prevalence rates to Irish population data. We can say with some certainty, therefore, that there are just over 30,000 people with dementia living in the country. The number of people affected by dementia is, however, different across counties and regions in Ireland, ranging from 1.31 per cent of the population in Leitrim to 0.55 per cent of the population in Kildare. This is because of the difference in the age structure of the population across counties and regions.

The focus on numbers should not distract us from the fact that dementia is likely to be experienced differently by different people. It is impossible to talk about average burdens, or normal symptoms, without doing damage to the complexity and uniqueness of the experience for people affected by the condition. These differences must be taken into account in the planning of services to meet the needs of people with dementia and their carers. The importance of an integrated and co-ordinated model of service provision that has the flexibility to adapt and respond to individual circumstances cannot be emphasised enough.
The resource implications of dementia

The economic and social burden of dementia on society is the value of all the resources used to prevent, diagnose, treat, and generally cope with the illness. Dementia is a costly condition, drawing on a variety of public and private resources. Costs fall on the health services, the social care services, the psychiatric services, families, and the voluntary sector. There is increasing pressure to define the cost components with a view to improving resource allocation and accountability in this area in the future. Recent developments in drug therapy, particularly the availability of new acetylcholinesterase inhibitors, offer new opportunities for people with dementia and will increase the pressure for earlier and wider diagnosis of the disease, leading to increased costs in the future.

We have assessed the overall resource implications of dementia in Ireland using Rothstein’s (1996) four category framework of: direct formal costs; direct informal costs; indirect formal costs; and indirect informal costs. Six main areas are covered in the cost analysis. These are as follows: mortality and life years lost, in-patient acute care, in-patient psychiatric care, residential long-stay care, family care, and primary and social care in the community. While the study includes all of the main areas of provision, the data set is incomplete, most notably with respect to day care costs, drug costs and the marginal cost of treating elderly people with associated dementia in acute care. The overall baseline cost estimate of £247 million should, in the circumstances, be seen as a lower-bound estimate. While the results indicate that the cost of illness associated with dementia is substantial; the most important aspect of the work is the distribution of the burden. The critical role of carers in maintaining people with dementia in their own home is reflected in the results showing that family care accounts for almost 50 per cent of the overall resource burden, based on an opportunity cost valuation of carer time.
Two changes to the calculations would increase the cost significantly and provide an upper-bound estimate of the burden of dementia. First, valuing carer time on the basis of average home help remuneration of £3 per hour instead of an opportunity cost basis would more than double family care costs. Second, including an estimate for the marginal cost of dementia in acute care elderly populations would increase the cost of dementia in this setting. Dementia and other forms of cognitive impairment are common in older people admitted to the general hospital for other reasons. The difficulty lies in estimating the additional costs, in terms of service use and length of stay, associated with dementia in this group. A major element of the additional cost of care is associated with patients awaiting transfer to more appropriate forms of care. The problem is that we do not have data on the extent to which dementia increases the waiting time for patients awaiting transfer. However, if we assume a dementia prevalence rate of 20 per cent in acute care elderly populations (Hickey et al, 1997), and that 18 per cent of all bed days are additional dementia-related days then acute care costs rise by £52 million. Including the revised estimates for family care and acute care would increase the overall cost of care to £450 million. Quite clearly, the consequences of dementia to society are serious and deserve more attention than they have received up to now. The purpose of this plan is to place the spotlight firmly on dementia services in this country.

**Policy background**

For ten years now the stated objective of public policy for people with dementia is to encourage and facilitate their continued living in their own homes for as long as is possible and practicable (The Years Ahead, 1988). Not surprisingly, The Years Ahead recommended additional services for people with dementia in the following areas: screening programmes to identify early dementia; the development of nursing and home support services under the supervision of the senior public health nurse; the

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1 This estimate has been provided by Dr. Desmond O’Neill.
expansion of day care facilities for people with dementia; and the
development of day hospital services for people with dementia. *The Years Ahead* also recommended special high support hostels and suitably adapted residential accommodation for people with dementia who could no longer be supported at home, linked to a multidisciplinary approach to care, under the direction of a consultant psychiatrist with special responsibility for the care of older people with severe dementia. Overall, *The Years Ahead* identified a significant gap between patient and carer needs and existing service provision in the area of dementia. Unfortunately, this gap has not been significantly bridged in the past ten years and services remain underdeveloped.

Despite the fact that the majority of people with dementia live at home, the emphasis on community care in official policy statements has not been matched by significant transfers of resources to the community sector during the past decade. If anything, community care services have become stretched in recent years as fewer long-stay beds have combined with binding financial constraints to place increasing pressure on the care system. Community care services remain patchy and variable across the country with no scientific or legislative relationship between need and provision. The implementation of the policies recommended in *The Years Ahead* has been slow and variable (Ruddle *et al*, 1997). The absence of a statutory mandate for community care services, apart from the public health nursing service, has had an inhibiting affect on the development of services for vulnerable older people in the past. Consequently, the critical element in bridging the gap between policy formulation and implementation is the establishment of a legislative basis for a greater number of community care services in the future.

**Balance of care issues**
The ability of people with dementia to remain in their own home is determined by a number of different factors. Four factors are particularly important:

- the extent of disability and functional impairment
- the socio-demographic characteristics of individuals
- the availability of family-based care
- the availability and accessibility of relevant community services

While the balance of care between the community and institution is very sensitive to marginal changes in any of these factors, the availability of family care is critical for people with dementia living at home. Families continue to provide the bulk of care for dementia sufferers, sometimes being on call 24 hours per day (Ruddle and O'Connor, 1993). Structural changes in society may have made it more difficult for families to care, but these changes have not necessarily diminished the basic willingness to care. Family care is not cheap, however, and imposes significant financial and emotional costs on carers. Community support services for people with dementia and their carers are under-developed and fragmented. Generally, people with dementia do not come into contact with the health and social services until a crisis occurs, involving the person with dementia, their carer, or both parties. Late intervention is, in turn, more likely to lead to institutional care, as the carer may no longer feel that she or he is able to cope. The result is a system geared to providing substitute in-patient care for people with dementia rather than providing anticipatory and on-going community care in partnership with patients and their family carers.

The cost of long-term residential care for people with dementia is a serious problem in all countries. The annual cost of a bed in public long-stay institutions in Ireland is difficult to estimate, given the variety in long-term care provision in this country. Estimates from official sources suggest that the annual cost of a long-stay bed in an extended care unit in the Eastern Health Board is just over £20,000 (Department of Social, Community and Family Affairs, 1998). The annual cost of care in less technologically
oriented long-stay units is likely to be lower, with one estimate suggesting annual per capita costs of approximately £15,000 (Blackwell et al, 1992). On the other hand, for long-stay institutions involved in comprehensive assessment and rehabilitation provision, the annual per capita cost of care may increase to over £30,000. Private fee paying accommodation is again very difficult to estimate given the wide variation in fee levels across the country, but residents and families can expect to pay between £15,000 and £20,000 per year depending on the location and type of accommodation. In the absence of private insurance, these costs can have devastating financial affects on patients and their families, and on the exchequer. Costs of this magnitude highlight the need for careful planning with respect to the placement of people with dementia. Given the high cost of residential care every effort must be made to keep people living at home. This can be done through increased spending for community care linked to the effective delivery of services to people with dementia. No one should be placed in residential care without first of all exploring whether a similar community-based budget might prevent admission, and allow them to continue living in their own home. For the most effective delivery of service, a case management approach to the organisation of care will be necessary to ensure that people with dementia get the services that they both need and value.

The urgency of the problem

The ageing of the population, the inadequacy of community care, and ongoing and binding public spending constraints have combined to focus public attention on pressing health and social care issues for people with dementia. Dementia poses particular challenges from both a clinical and policy perspective because of the heterogeneous nature of the condition, its multiple causes, the debilitating nature of the disease, and the absence of a cure. It has not, however, received the attention it deserves because it has largely been seen as ‘tomorrow’s problem’. This is now changing because the increasing proportion of the ‘very old’ within the population has placed the spotlight firmly on dementia, given the higher prevalence rates of dementia in older age categories. The accumulating evidence of unmet needs amongst people with dementia and the realisation that public expenditure constraints are likely to become even more binding within evolving Monetary Union strictures within the European Union has added to
concern about future service provision for people with dementia and their carers. The reality is that the current system of care for older people with dementia is seriously under-funded, even if there is likely to remain strong resistance to any attempt to commit more public expenditure to this area in the future.

Future demographic projections point to an increase in the number of older people, particularly in the oldest age categories, a long-term decline in the pool of potential female carers, and a general decline in the proportion of the population of working age. The number of people over 65 years is projected to increase by 30 per cent by the year 2011, with the number of people over 80 years expected to increase by two thirds in the same period. These changes in population and labour market structures will lead to an increase in the number of people with dementia. By the year 2011 we will have over 7,000 more people with dementia than we have now. Demographic change, while unevenly spread, will place increasing pressure on public resources at a time when demands are likely to be high anyway, arising from the rising cost of welfare, pensions and other supports for older people.

There has been a lack of urgency in dealing with the problems of people with dementia and their carers that would not have been tolerated in other areas of the health services. Many patients with dementia fall between the cracks of the health care system, between purely medical provision and purely psychiatric provision. People with dementia may be discriminated against because of a lack of awareness and training amongst providers. In some cases the discrimination may be more perverse. A long-term care facility faced with a choice between a cognitively intact person and a demented one will generally choose the former. There is, however, an emerging consensus that the inadequate support available to dependent older people is no longer acceptable. Support for action has come from a number of different organisations, including the National Council on Ageing and Older People, various non-governmental organisations, voluntary groups,
the Alzheimer Society of Ireland, health professionals, and carers' representative groups.

This document is an attempt to put in place an action plan for dementia care in Ireland which reflects the genuine concern among the various providers and interest groups about service provision in this area. The aim of the plan is to strengthen the capacity of current programmes to provide dementia care services and to facilitate the development of new programmes in both community and secondary care settings. The emphasis is on providing high quality care geared to meet the individual needs of people with dementia. The concepts of health gain and social gain have been explicitly used in health care planning documents to emphasise the importance of quality of care for all patients and clients of the health services (Department of Health, 1994). Even if both of these concepts have often been poorly defined, and remain particularly elusive in the case of older people with neuro-degenerative conditions, they remain an important symbol of the importance of outcomes in the area of dementia.

**Methodology**

The plan is a reflection of the views of health care professionals and policy-makers working in the area of dementia. We undertook extensive consultation with the national representative organisations associated with the professions relevant to dementia care. The following organisations were consulted over a six-month period:

- The Carer’s Association
- Consultant Geriatricians
- Consultant Psychiatrists specialising in the Psychiatry of Old Age
- The Irish College of General Practitioners
- The Institute of Public Health Nursing
- Irish Senior Citizen’s Parliament
- Sonas aPc
We met each of the groups separately and the interviews were, for the most part, unstructured. Prior to the meeting, people were sent a two page outline of the range and type of issues that we were likely to cover during the consultation, thereby providing a framework for the face-to-face discussions that followed. The main headings for the discussion were as follows: an overview of services, the diagnosis of dementia, community care services, support for carers, non-residential alternatives to home care, residential care, and co-ordination issues. Respondents were given the choice of following this agenda, or concentrating on the topic/s of most interest to them. People varied in how they responded to the interview, but most people valued the opportunity to explore the issues in a comprehensive manner. The consultations were followed, in October 1998, by a one-day seminar, at which people were given feedback on the progress of the plan and an opportunity to contribute further to its development.

**Philosophy and principles**

The development of a philosophical framework is necessary in order to provide an enduring reference point for the planning of services for people with dementia. The philosophical framework proposed in the plan is based on respect for the autonomy of individuals suffering from the disease. It is
easy to forget about the person with dementia in the search for optimal care strategies and efficiency in resource allocation. But, even if autonomy has to be qualified in the case of a person suffering from dementia, it is a good starting point, because it focuses on the person as the key to the whole process of care and not as an object of care. The person with dementia, by virtue of their very existence, their emotions, their senses, must take centre stage in any plan. The person remains sacrosanct even if the illness is difficult to both define and understand. Once we establish solidarity with the people we want to help, and their lives become part of some shared sense of humanity or community, it becomes relatively easy to derive principles for the provision of services.

The issue of resource allocation for people with dementia cannot be discussed in a vacuum. We must have principles against which progress can be measured to enable us to make informed comment about the advantages and disadvantages of different approaches to care. Any set of principles must acknowledge the primary role of the person with dementia in the process of care in keeping with the philosophy outlined above. This is very important as it confirms the resource allocation process as a means to an end, and not an end in itself. There is, of course, no scientific way of devising principles. Any set of principles will contain both normative and subjective elements. What follows, therefore, are six principles, drawn from a variety of sources, which we believe should underlie the action plan for dementia care:

- respect for the preferences and rights of the person with dementia
- the comprehensive provision of care
- bias towards home care solutions, including support for carers
- care requirements to determine funding, not vice-versa
- access to services on the basis of need, not income or geography
- national quality targets and outcome targets to underlie provision

The purpose of these principles is to shape the action plan for dementia, with the overall objective of maximising the well-being of people with dementia.
We want to close the gap between the quality of life that people with dementia currently experience and what they might optimally achieve with a more intensive, comprehensive, and co-ordinated approach to service delivery. For this to happen, the plan will have to nurture and develop the whole range of capabilities of people with dementia, thereby allowing them to reach full expression within the limitations imposed by their condition. This is a difficult and time-consuming task since it requires a detailed and intimate knowledge of the whole lives of people with dementia. But it is a task that must be done if we are to reach out to people with dementia as people and not as passive objects of care for whom concern is modulated by the decline in their mental powers.

**Pathways to care: primary and community care services**

In the majority of cases, dementia can be dealt with at the level of primary and community care provision. Early diagnosis is critical for people with dementia. For that reason clinical standards and competencies for early diagnosis of dementia should be developed and people with dementia should be informed of their condition at the earliest possible moment, unless there are strong medical or social reasons for withholding such information. Early diagnosis allows for better planning, both in terms of care provision and in terms of personal issues. Early diagnosis facilitates more timely, and therefore more effective, community care intervention and leads to less crisis management for people with dementia.

To encourage and facilitate early diagnosis, information and training should be provided to general practitioners through opportunistic or targeted assessment using tools sensitive to the detection of dementia in primary care. Public health nurses should also receive training in dementia assessment and be given more resources to work with in order to make identification worthwhile. Early diagnosis would be facilitated by the launch of a public information campaign designed to raise awareness of dementia among the general public.
The current under-funding of community care services needs to be addressed without delay. This can be done through the provision of additional, flexible, and appropriate community care services, particularly in the areas of home support services, day care, day hospital, and respite care. To facilitate the effective delivery of services to people living at home new ways of co-ordinating services must be adopted. The most effective way of ensuring flexible and integrated care provision is through the introduction of a case management model to plan and co-ordinate services for people with dementia and their carers within geographically defined catchment areas in each health board. Within the case management model, the person with dementia should, where possible, play a major role in developing a care plan that suits his or her own particular preferences and circumstances. The case management model should be introduced on a pilot basis in two health boards as soon as possible.

Carers should also have a major input into placement decision-making and service delivery with respect to people with dementia. Carers require support from the moment of diagnosis. Carers are currently providing the bulk of care to people with dementia and they show no sign of reducing their current commitments in this area. What they want is a greater acknowledgement of their contribution to the care process and access to help and support from official sources. It is important to make the point that support from official sources must be flexible and must be available when and where carers value it most highly. Payment for carers is another issue that needs to be resolved. The current Carer’s Allowance is too restrictive and should be replaced by a non-means tested Constant Care Attendance Allowance of £100 per week for carers. Eligibility for this allowance should be based on an assessment of care recipient needs and dependency made by the relevant case manager. This would significantly increase the numbers qualifying for the allowance and would be an important signal to carers of the value placed on their work by society. Carers should also receive training in the care of people with dementia, as well as counselling services,
if required. Counselling should be available during the caring process and in
the months following the death of the person being cared for by the carer.

Day services for people with dementia need to be expanded. Dementia-
specific day care places should be provided in each district or community
care area, in buildings suitable for people with dementia, and with staff who
are trained in the care of people with dementia. We also recommend an
increase in the number of respite beds in community hospitals to a norm of
1:10,000 elderly population. This should be accompanied by the
development of in-home respite services for people with dementia as a
mechanism for providing relief for carers, thus ensuring their long-term
ability to care for the person with dementia.

Home care services are very important in allowing people with dementia to
continue living in their own homes. The problem is that home care services
in many health boards are under-developed, while there is very little choice
or flexibility on offer from existing services. A new approach offering
comprehensiveness and flexibility is required, incorporating both ‘twilight’
provision of services and weekend coverage, if needs are to be met in this
important area. People with dementia require the provision of flexible,
continuous and legislatively based home help and home sitting services
g geared to meet individual needs and circumstances. The existing work of
the voluntary sector in this area provides an important starting point for the
expansion of both home care and day care services. There is also an
important role for social workers in the care of people with dementia living
in the community. That role needs to be acknowledged through the
establishment of dedicated posts for social workers at community care level,
working with chronic, frail, older people and their families.

In summary, the majority of the needs of people with dementia and their
carers should be met by what is put in place at the level of primary and
community care. This involves the provision of a flexible network of
services that will meet the changing needs of those with dementia and their
carers. The dignity and autonomy of people with dementia will be best
served by the development of individualised care plans mediated through
case management structures. General practitioners are critical agents in the
process of care since they are often the first people involved in making a
diagnosis of dementia. The public health nursing service is also important
since nurses are likely to see most of the vulnerable people with dementia
living at home, and provide a link to many of the support services that people with dementia need and value. Day centres are also an essential component of care provision for people with dementia. People with milder degrees of dementia, and who have no behavioural problems, can be managed in general day centres, which are available to all elderly people in a particular community. People with severe dementia, or who have problems with wandering, will require specialised dementia day centres at primary care level, as currently provided by the Alzheimer’s Society in some parts of the country. Respite care, both in-patient and at-home types, is also important depending on the stage of the disease and the particular needs of patients and carers. Whatever the service, the key element in primary and community care is flexibility of supply in response to the expressed needs of people with dementia and their carers.

**Pathways to care: secondary level care**

There are some people with dementia who will require the services of specialist dementia teams in response to the complexities arising from their condition. These specialist teams form the backbone of secondary level support services for the more complex cases presenting in the primary and community sectors. Secondary level services in this country are two in number: Medicine for the Elderly and Psychiatry of Old Age. The role of Medicine for the Elderly lies with both the diagnosis of dementia and the assessment and management of people with dementia who have medical problems. The cases seen by Medicine for the Elderly include people who have medical problems that are beyond the remit of the general practitioner and those who present with diagnostic problems. The continued development of specialist geriatric departments is a key element in the care of people with dementia. Psychiatry of Old Age is the mirror image of Medicine for the Elderly in that instead of dealing with physical problems, it deals with mental health problems in elderly people. About 50 per cent of the work of Psychiatry of Old Age services are in the area of dementia. The service has specific responsibility for people with dementia who have severe behavioural problems, such as aggression, associated with their dementia, or psychiatric symptoms, such as delusions, depression, or anxiety, associated
with dementia. Like Medicine for the Elderly, Psychiatry of Old Age may also play a role in diagnosis but continued involvement in such cases only occurs where there are associated behavioural or psychiatric symptoms.

Psychiatry of Old Age services are under-developed in Ireland. Consequently, there is an urgent need to accelerate the development of Psychiatry of Old Age services beyond the limited, urban-based, services that are currently available in the country. We recommend the adoption of a planning norm of one consultant in old age psychiatry per 10,000 people aged 65 years and over. Each should be provided with an appropriate multi-disciplinary team, day hospital facilities based in a general hospital setting, acute psychiatric beds, and long-stay psychiatric facilities. For acute beds, the appropriate norm is 1:1,000 elderly population; for continual care beds, the appropriate norm is 3:1,000 elderly population. The service should also have good access to non-psychiatric day and residential care. Teams will require the direct involvement of community psychiatric nurses and a specialist social worker. Teams should also include psychologists and occupational therapists, as well as having access to speech and language therapists, physiotherapists and dieticians, depending on the specific needs of the patient. This plan allows for the introduction of five new Psychiatry of Old Age services per year over the course of the plan, in addition to the services already sanctioned but not yet in operation. By the end of the plan there should be twenty new posts in place.

Multi-disciplinary teamwork is an essential element of the shared approach to the delivery of services to people with dementia. So also is effective communication between the various specialities, and between secondary care services and primary/community care services. Currently, liaison between the geriatric and psychiatric services is mainly informal. To ensure effective secondary care provision, existing services must be linked through more formal models of co-ordination and co-operation, associated with evolving case management structures at the level of service delivery. A common training programme for all professionals working with people with dementia will help foster co-operation among the various professions in both the primary and secondary care sectors. The establishment of the Dementia
Services Information and Development Centre at St. James’s hospital as a national centre for training and development is an important step in developing appropriate and common training programmes for health professionals working in this area.

**Pathways to care: residential and nursing home care**

The vast majority of people with dementia who are in residential care in Ireland are cared for within generic elderly care facilities. This is likely to continue in the future as people with easily manageable dementia will continue to be looked after in general category long-stay care, both in the public and private sector. However, the care needs of people with dementia, even those not suffering behavioural or psychiatric problems, are likely to be different to other patients. Indeed, given the heterogeneity of dementia, differences within the group of people with dementia may be greater than the differences between some older people with dementia and older people without dementia. Therefore, services in generic long-stay facilities must be augmented to ensure that people with dementia have access to appropriate care, and that appropriate referral procedures are in place should the care needs of residents change.

We recommend the development of effective training programmes for staff working in all types of residential care facilities. New initiatives in residential care provision will not succeed without the concomitant training of staff working in these units. Training programmes should be designed to facilitate a person-centred approach to care and service delivery, which recognises the uniqueness of residents with dementia. Generic long-stay facilities are unsuitable where there is serious or repeated behaviour disturbance. For people with severe and persistent dementia-related behavioural problems, we recommend specialist care in long-stay psychiatric units within Psychiatry of Old Age services. These units should be staffed by psychiatric nurses.
New investment in both generic and special residential care facilities is required if we are to follow the international trend towards small, safe, domestic-style, accommodation for people with dementia in long-stay care. In many cases, this investment will take the form of adaptations to existing capital stock, but it may also require the provision of new buildings in some circumstances. Design features, such as colour, lighting, furniture, heating, and security, have largely been ignored in the provision of long-stay facilities in this country. There is an urgent need to invest in design features in long-stay accommodation, given the accumulating evidence on the effect of design on the well-being of people with dementia.

The process of care in residential accommodation is a very important aspect of good practice for people with dementia. Process is concerned with the form and delivery of care for dementia patients within residential facilities. More attention should be focused on the social and sensory needs of long-stay residents through the support of various psychosocial interventions such as reminiscence therapy, validation therapy and reality orientation for people in the early stages of dementia. There are many different approaches to overcoming communication difficulties in people with dementia. Music and touch are particularly important in stimulating a communicative response from people with dementia. Retained communicative abilities, if activated, will enhance the quality of life of people with dementia in three main ways: through increasing interactions with other people and with the environment; through having their needs better understood; and through being able to give some meaningful expression to their feelings. We recommend that social, psychological and sensory needs be given equal weighting to physical needs in residential care settings, and that management structures support a holistic and person-centred approach to care. Training for staff in the delivery of these types of interventions is an important aspect of more effective residential care for people with dementia. So also is the ongoing monitoring and dissemination of models of best practice leading to the eventual elimination of sub-standard accommodation and poor quality care. Training
and quality of care issues should be more formally incorporated into existing regulatory structures for the long-stay sector.

**Special need groups**

The application of EURODEM prevalence rates to Ireland suggests that there are approximately 2,000 people with dementia under the age of 60 in the country. Younger people with dementia do not fit easily into the services designed for their older counterparts. It is usually a case of choosing from a range of services set up with other needs, or age groups, in mind. Younger people with dementia are likely to react differently to the disease than people in older age categories. They tend to be more physically fit and active and to have more responsibilities in terms of employment and families. Sometimes early dementia is associated with other conditions such as Down’s Syndrome. There may also be difficulties with diagnosis, sometimes related to general practitioners having very little experience with early onset dementia. We are only now recognising that people with early onset dementia have needs which are unique and distinct from their older counterparts. Public awareness of early onset dementia is currently low and tolerance for younger people with dementia is likely to be less than for older people. More information on the specific characteristics of early onset dementia would go some way towards developing an understanding among the public of the difficulties of younger sufferers.

We need to develop appropriate and individual-specific community care services for younger people with dementia. Day care and respite care should play important roles in the care of younger people with dementia. We also need to be more aware of the needs of families given that early onset dementia occurs at a different stage of the family life cycle. Families and patients may need high levels of professional support at the time of diagnosis, particularly in the areas of counselling and emotional support. Early diagnosis is important because younger people with the disease are
likely to have more commitments and early diagnosis may provide an opportunity for people to plan for the future.

Teamwork is an essential aspect of the approach to care for people with early onset dementia. For people with Down’s Syndrome who also have dementia, there needs to be high levels of co-operation and understanding between the mental handicap services and the various services for people with dementia. Training in dementia care is necessary for people working in the mental handicap services to ensure that all staff working with people with Down’s Syndrome who also have dementia should have the skills and competencies necessary to deal with both conditions. Similarly, health professionals from the various services for people with dementia should receive training in how to relate to people with a mental handicap.

Policy implementation issues

For many years now the stated objective of public policy for vulnerable older people is to encourage and facilitate their independent living in their own home for as long as is possible and practicable. The emphasis on community care in official policy statements has not been matched by the significant transfer of resources to the community sector. Community care services remain patchy and variable across the country with no scientific relationship between need and provision. Consequently, it is at the level of policy implementation that most attention should be focused if the increase in resources to community care, which is critical to the success of this plan, is ever to become a reality. For that reason, the establishment of a committee to oversee the implementation of the plan should accompany this document. The committee would monitor progress with respect to the attainment of service targets for people with dementia outlined in the plan.

There are three crucial relationships with respect to policy implementation: the relationship between the centre and the local; the relationship between the statutory and voluntary sector; and the relationship between the public
and private sector. With regard to centre-local relationships there must be a renewed emphasis on meeting existing policy objectives for people with dementia and their carers, through legislatively based support for the provision of community care services. Providers should be involved in the formulation of policy, with respect to both planned provision and the resource implications of new forms of delivery. The role of the voluntary sector would also be enhanced by their more formal involvement in both the formulation and implementation of policy with respect to people with dementia and their carers. There also needs to be more consistent and longer-term funding arrangements between the health boards and the voluntary groups providing services to people with dementia.

Not enough is being done to release the considerable potential for complementary provision between the public and private sectors. We need to explore ways of developing co-operation between the public and private sector. Many nursing home proprietors feel cut off by the absence of any public services going into their homes. There is also concern among nursing home proprietors that subvention payments for people with dementia in private nursing homes are too low to support the type of services required by these patients. While there may be some substance to this claim, existing subvention funding for private nursing homes tends to crowd out spending on community care services, which, in turn, creates additional demand for nursing home places. For that reason, even if subvention payments are to be increased, no one should be granted a subvention for private nursing home care unless it has been established that a similar amount of money would not have enabled them to remain in their own home. This approach would lead to a more effective use of resources for people with dementia and would be more in line with current policy statements about the primacy of community care.

**Costs and funding**
The recent comprehensive review of developments in care of the elderly is critical of the slow rate of progress towards the development of a genuinely community-based approach to the long-term care of dependent elderly people (Ruddle et al., 1997). While there remains a general consensus that the long-term care of dependent elderly people should be located in the community, which is reiterated in this plan, not enough has been done to develop community care services in a comprehensive and integrated manner. There is uniform agreement that a major gap exists between the needs of elderly people with dementia and existing service provision. This plan contains a number of different recommendations designed to bridge the gap between need and existing provision for people with dementia. The overall cost of delivering the increase in services envisaged in the plan over a three-year period is £46 million, or approximately £15 million for each year of the plan. This is equivalent to an annual grant of £500 for each person with dementia in the country. When presented in this way, the cost is minimal relative to the potential gains to be had from the implementation of the plan.

We cannot, however, rely on increased public spending to solve all of the problems in this area, given the continuing constraints on social expenditure originating in our adherence to, and commitments arising from, the Maastricht criteria for Monetary Union. We will have to explore innovative ways of financing increased spending for people with dementia, through new forms of social insurance, and the nurturing and further development of the social economy. In the short term, we recommend additional resources for dementia care financed from general taxation; in the long-term we recommend moving to a social insurance system for the funding of long-term care, which would include services for dementia. We also see potential in the development of the social economy and suggest training and seed capital funding for the nurturing of social entrepreneurship at a local level as a means of meeting the needs of people with dementia and their carers in a flexible and innovative way.
Recommendations

1. We recommend that clinical standards and competencies for early diagnosis of dementia should be developed and that people with dementia should be informed of their condition at the earliest possible moment, unless there are strong medical or social reasons for withholding such information.

2. We recommend that information and training should be provided to general practitioners to facilitate and encourage the early diagnosis of dementia through opportunistic or targeted assessment using tools sensitive to the detection of dementia in primary care.

3. We recommend that public health nurses should receive training in dementia assessment and be given more resources to work with in order to make identification worthwhile.

4. We recommend the launch of a public information campaign designed to raise awareness of dementia among the general public.

5. We recommend the introduction of a case manager model to co-ordinate services for people with dementia and their carers within geographically defined catchment areas in each health board. The model should be introduced on a pilot basis in two health boards as soon as possible.

6. We recommend that carers should have a major input into placement decision-making and service delivery issues.

7. We recommend the replacement of the Carer’s Allowance with a non-means tested Constant Care Attendance Allowance for full-time carers based on an assessment of care recipient needs and dependency made by the relevant case manager.

8. We recommend the development of information and counselling services for people with dementia and their carers.
9. We recommend that dementia-specific day care places be provided in each district or community care area in buildings suitable for people with dementia and with staff who are trained in the care of people with dementia.

10. We recommend the development of day hospitals within each Psychiatry of Old Age Service for people with dementia who have associated behavioural problems or psychiatric symptoms.

11. We recommend an increase in the number of respite beds in community hospitals to a norm of 1:10,000 elderly population and the development of in-home respite services for people with dementia as a mechanism for providing relief for carers and ensuring their long-term ability to care for the person with dementia.

12. We recommend the provision of flexible, continuous and legislatively based home support services for people with dementia.

13. We recommend the development of community-based occupational therapy services and social work services for people with dementia living at home.

14. We recommend the adoption of a planning norm of one consultant in old age psychiatry per 10,000 people aged 65 years and over, each being provided with an appropriate multi-disciplinary team and psychiatric facilities, including a day hospital and acute and long-stay psychiatric beds together with good access to non-psychiatric day and residential care.

15. We recommend the adoption of a ratio of 1:4,500 elderly population for community psychiatric nursing services within the framework of an expanded Old Age Psychiatry service.

16. We recommend that geriatric medicine facilities be adequately staffed with full interdisciplinary teams, and encourage close co-operation between geriatric medicine and Psychiatry of Old Age services.
17. We recommend dementia awareness training for medical and nursing staff in acute hospitals, particularly for people working in accident and emergency departments, to help them identify the symptoms of dementia in patients under their care.

18. There should be undergraduate training in dementia for doctors, and chairs in geriatric medicine and the Psychiatry of Old Age in each of the universities.

19. We recommend the provision of small-scale, domestic-oriented, specialist units attached to conventional long-stay facilities for people with dementia without significant behavioural problems, but who need long-stay care.

20. We recommend that social, psychological, artistic and sensory/communication needs be given equal weighting to physical needs in residential care settings, and that management structures support a holistic and person-centred approach to care.

21. We recommend the development of effective training programmes for staff working in all types of residential care facilities. These training programmes should be designed to facilitate a person-centred approach to care and service delivery.

22. We recommend that particular attention should be paid to the needs of people with early onset dementia with appropriate care packages drawn up to reflect the special circumstances of people in this group and their carers.

23. We recommend specially designed and integrated care packages for people with Down's Syndrome and dementia, delivered within the mental handicap programme, with training in dementia care facilitated by the Old Age Psychiatry and/or geriatric medicine services.

24. We recommend the establishment of an implementation committee to oversee the development of this plan.
25. We recommend that the Dementia Services Information and Development Centre at St James’s receives appropriate funding to allow it to function as a national centre for the identification and dissemination of information on best practice in dementia care in Ireland.

26. We recommend a renewed emphasis on meeting existing policy objectives for people with dementia and their carers, through legislatively based support for the equitable provision of community care services.

27. We recommend that services for people with dementia be delivered locally, in a flexible manner, within the framework of new case management structures, wherever possible.

28. We recommend that the voluntary sector should be more formally involved in both the formulation and implementation of policy with respect to people with dementia and their carers.

29. We recommend more consistent and longer-term funding arrangements between the health boards and the voluntary groups providing services to people with dementia.

30. We recommend an audit of the number of people with different types and severity of dementia in private nursing homes; an evaluation of the public subsidy arrangements for these patients; and greater integration of public and private production in the care of people with dementia.

31. We recommend a more formal emphasis on multidisciplinary teamwork in the care of people with dementia within the integrative framework of a case management model of service delivery.

32. We recommend the development of the social economy and the nurturing of social entrepreneurship at a local level as a means of meeting
the needs of people with dementia and their carers in a flexible and innovative way.

33. **In the short-term**, we recommend additional resources for dementia care financed from within existing health and social care budgets; **in the long-term** we recommend further exploration of moving to a social insurance system for the funding of long-term care.