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together with colleagues throughout the European Union

## **European Transnational Alzheimer's Study (ETAS)**

European Analysis of Public Health Policy Developments for  
Alzheimer's Disease and Associated Disorders of Older People and  
their Carers

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## **Acknowledgements**

This report is the culmination of a major research project involving Case Study Writers in each of the Member States of the European Union. Without their work, this report simply could not have been produced.

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# INTRODUCTION

## Background

The growth in the prevalence of dementia over the last few years has been constant and steady, linked with demographic changes in the European population that show a rise in the number of elderly people. In Britain alone, estimates suggest that there are between 0.5 and 1 million people suffering from some form of dementia (OPCS, 1991). There is also evidence to suggest that Alzheimer's Disease (AD) is the most common form of dementia and accounts for 50% of all classified cases. It is thought that 6.2% of the 1996 UK population aged 65+ will have some form of cognitive disability, 36% of whom are estimated to be resident in institutional care where they make up half of the residents (Meltzer et al., 1995). Data generated by the Eurodem Study (Hofman et al. 199 ) reveal similar prevalence estimates for the rest of Europe. It is also clear from these figures that the prevalence of both dementia and cognitive impairment increases dramatically with age.

The uniqueness of the problems in caring for an older person with cognitive impairment means that in both formal and informal care situations specialist skills and facilities are required, even for apparently simple problems (Meltzer et al, 1995). The complexity of the different needs of people suffering from dementia makes the question of provision of services problematic, however, and the type of information provided in the Meltzer report, giving estimates of the characteristics of older people with care needs, could go some way towards more detailed planning of service provision. Hence, the European Parliament's decision to provide new funding specifically for the study of Alzheimer's and other neuro-degenerative diseases in Europe in 1996.

Traditionally, the standard paradigm for the understanding of dementia has been as an organic mental disorder (Forstl et al., 1991; Cutting 1987; Burns et al., 1990; Brevit and Ruben, 1989) drawn largely from the medical model (Katzman, 1985; Lawson et al., 1988) and has been treated as such. This, whilst being of vital importance, undervalues the human issues involved in the care of people with dementia (Kitwood, 1997). There is no real prospect for a cure in the near future, despite the developments in drug therapies; and European countries,

including the UK, will need to plan appropriate services to meet increasing demand (O'Donovan, 1990).

The development of people-centred values and principles behind services for people with dementia combines social and psychological approaches with the medical model. The need for innovation in care practice and service development in order to sustain these principles has been one of the assumptions behind this research.

Of relevance is the UN Principles for the Protection of Persons with Mental Illness, 1991. *Principle 1*, on fundamental freedoms and basic rights, states that persons have a right to the best available mental health care and that these same persons should be treated with humanity, dignity and respect.

Services should seek to maintain personal respect as part of a person's birthright, and to reflect it in standards of care practice. Most recent discoveries for promoting the well-being of people with dementia use a humanistic approach (Kitwood et al., 1995).

Also relevant in this context are the principles agreed for services to people with dementia in the UK, as expressed in the 1986 King's Fund Project Paper No. 63, "Living Well into Old Age":

- *"People with dementia have the same human value as anyone else irrespective of their degree of disability"*

People with cognitive disabilities should be treated with the same respect and quality of life afforded to others. They should not be identified by a diagnostic category and should have the freedom to choose where they live, the activities they participate in and who they spent their time with. The services they receive should be 'first class, skilled, prompt and relevant'.



- *“People with dementia have the same varied human needs as anyone else”*

Physical care is not the only need of any individual, and isolation from familiar and community life is detrimental. Assessment procedures should cover a range of needs and services should be delivered in appropriate setting. Services should be local, accessible and responsive to individual need.

- *“People with dementia have the same rights as other citizens”*

Decision-making is an integral part of the human condition. To remove an individual’s right to be involved in the decision making process could lead to an infringement of legal and civil rights. The right to exercise control and make choices about some aspects of everyday life should be maintained as long as possible and thereafter be protected through advocacy. Professional practice has improved in all types of residential care but there is evidence that the Patient’s Charter standards of privacy, dignity and information are still not automatically respected (Biggs, 1995).

- *“Every person with dementia is an individual”*

As each person is individual so their needs will be and their care should reflect this. “There is no longer any excuse to condemn people with dementia to a passive and unconstructive domestic or institutional environment” (BPS, briefing paper 2, 1994).

- *“People with dementia have the right to forms of support which don’t exploit family and friends”*

Care should be of an appropriate nature and staff should be appropriately trained. Informal carers should not be subject to exploitation. Support and services should be readily available to informal carers. Informal carers should have a voice as to when professional care is needed. The rights of informal carers need to be safeguarded.

Social and health care policies in the UK since the Community Care Act in 1990 have moved towards enabling people to stay in the community wherever possible. This policy is reflected in the reports from most of the countries of the European Union. A House of Commons Health Select Committee recommended that seven principles should be adhered to in relation to long term care. These included maximisation of independence, self respect and choice for the individual, equitable practice and the improvement of long term care whilst providing support, encouragement, training and finance for informal carers.

A Health of the Nation handbook on mental health published in 1997 outlined three guiding principles: equity, efficiency and responsiveness. Older people should have the same entitlement as other citizens. They should be able to expect to live in their own homes and be safe from neglect and abuse, and they should be able to rely on professionals delivering services to be sensitive to their individual needs and preferences. The same principles have, to some extent, guided strategic developments for older people throughout Europe.

For the individual, these principles advocate maintaining choice and independence, having control over treatment and available and appropriate care. They reflect sensitivity to needs, active support and the monitoring and review of intervention. They also acknowledge the need to recognise and retain individual cultural, social and gender needs. Also recognised are the rights of informal carers.

The support of cohesive services and collaboration between health and social services are inherent in good service, as are sensitivity and commitment to the needs of individuals and their carers. Also reflected is the need for appropriate and proper information and training for informal and formal carers and professional staff, and the uniqueness of the needs of people involved.

## **Aims of the Project**

Against this background, this project aimed to do the following:

1. To examine working definitions of cognitive impairment across Europe, including the ways in which these definitions are interpreted; and to demonstrate the clinical, social and

legal implications of these definitions, eg how a distinction is drawn between mental/physical frailty, with and without impairment of mental capacity.

2. To investigate the relationship of the definitions of cognitive impairment in elderly people with policy and practice across Europe. This involves a macro-level/secondary data analysis of service programmes to ascertain whether they reflect the policy intentions.
3. To pinpoint landmarks in the disease process (indicating the need for a decision about whether to intervene) across European nations.
4. To explore the factors associated with cognitive impairment and the identification of Alzheimer's Disease and other neurodegenerative disorders in elderly people in each country, including how health and social gain are measured, eg, the clinical detection of memory impairment and/or a breakdown in the capacity to cope, and the support networks available.

## **Methods**

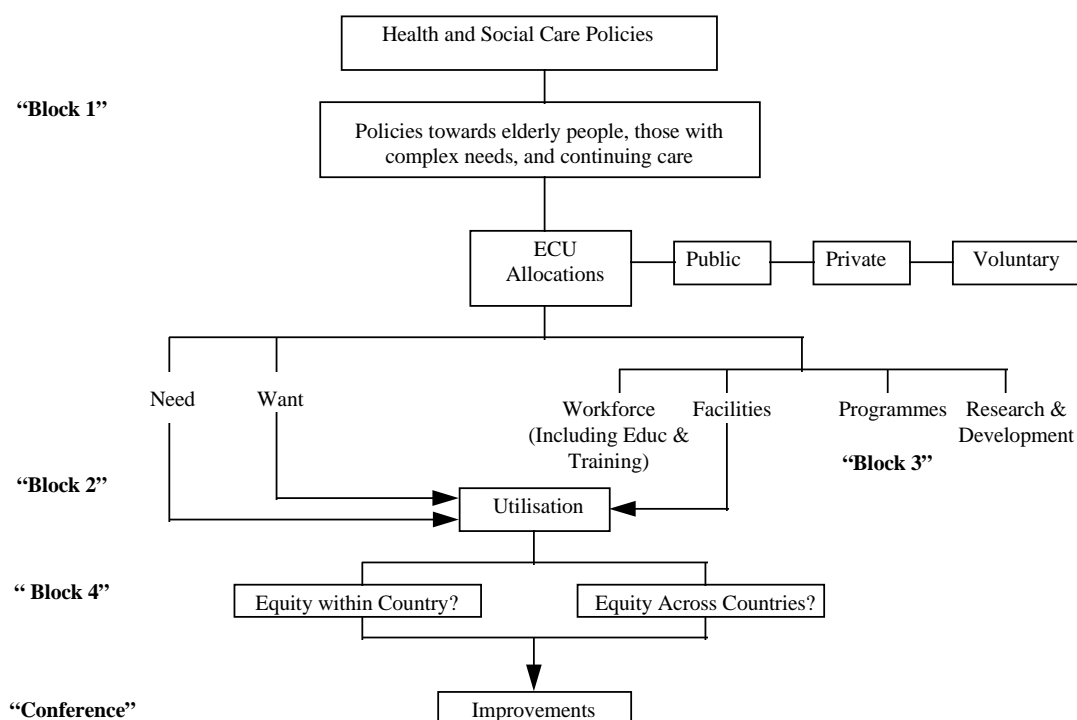
The project began at the end of 1996, and was completed in September 1998. It had three main elements:

- Case study reports on each of the fifteen member states of the EU, written by researchers resident in each of the countries. They drew mainly upon secondary data, supplemented where necessary by interviews with key informants and questionnaires to relevant organisations;
- Synthesis of these data by the Principal Investigators and Co-ordinating Analysts, drawing upon extensive discussions with the Case Study Writers, including two extended workshops in Cardiff (in the Spring and Autumn 1997) which explored and developed the emerging inter-connecting themes;
- A European Conference held in April 1998 in Dublin, in which the case study reports were presented in summary form, and where there were presentations and structured discussions of many of the key emerging themes. Over 250 people attended this meeting.

This report draws upon all three of these elements.

The work was guided by a ‘quasi-economic’ framework, which considered in turn of issues relating to the broad policy framework, the demand for services (influenced by ‘needs’ and ‘wants’), and the supply functions:

**Figure 1 Framework for the analysis**



Each of the Principal Investigators took the lead on one of these ‘blocks’ of data. The final elements, which emerged as part of the synthesis of data, were an examination of issues of equity, and consideration of ways of improving the provision of services for people with AD and their carers

Each Case Study Writer was situated within a major research or other specialist establishment, and therefore drew upon the expertise and resources of their colleagues and institutions in carrying out their research. Their reports followed the structure set out in Appendix 1, and were also peer-reviewed in their own countries before being submitted. There was considerable dialogue between the Principal Investigators/Co-ordinating Analysts and the Case Study Writers throughout the project, including two extended meetings in Wales involving the whole team. The conclusions reported here, therefore, are the product of this

collaborative work, although the final drafting was the responsibility of the Principal Investigators and Co-ordinating Analysts.

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\* Further details are available in Appendix 2

## **Structure of this report**

This document is a summary of the evidence presented in full in each country's Case Study Reports. It presents the conclusions of the project in each of the areas that were investigated; and detailed information on individual countries is contained in that country's report. Full copies of the Case Study Reports are available on request from the Welsh Institute for Health and Social Care, University of Glamorgan, and summarised versions of the majority are available on the Web Page of the Institute (<http://www.glam.ac.uk/wihsc/Alzheim.html>). A full set of in-country bibliographic references are contained in the original case study reports.

This report falls into four main sections:

- Chapter One summarises the findings relating to the national policy context across the Union, focusing upon those aspects of the level of social support for sufferers and their carers which is determined by national government and agencies.
- Chapter Two focuses on the methods and measures used in the detection and diagnosis of Alzheimer's disease and neuro-degenerative conditions in elderly people. It considers how clinical and other decisions are made by the different professional bodies and how this determines access to care and financial support.
- Chapter Three investigates the implementation of national policies in the pattern and quality of current services and future service plans.
- Chapter Four contains the conclusions and recommendations for policy makers and practitioners across Europe.

# **CHAPTER ONE**

## **THE NATIONAL POLICY CONTEXT ACROSS EUROPE**

### **Introduction**

This chapter documents the findings related to the investigations carried out both on general national health and social care policies across the fifteen European member states and also in specific policies related to old age care, dementia care, and support. As such, it summarises the work undertaken in Block 1 – the policy framework.

### **Recent History of Policy Developments**

The most striking feature to emerge from this review of the recent history of policy in this area is the movement towards a substantial degree of agreement on key principles of policy. Many of these are now enshrined in the policy frameworks of all member states, and others adopted in most countries.

This convergence has taken place only within the last 10-15 years, with different countries moving at different rates towards the current position of near consensus. The driving forces fall into two categories:

#### ***Politico-economic***

Policy has been driven by a recognition of the rapidly growing demands of older people in general (largely as a result of their increasing numbers), and of older people with dementia in particular, and the financial and political implications of failing to provide the most cost-effective patterns of state and other support for them and their carers. For example, all member states share similar future demographic profiles (increasing numbers of elderly - and very elderly - people, and a decline in the proportion of people of working age); this, combined with research evidence of the prevalence of dementia, quickly revealed a potential future problem. In some states, such as Finland, one particular epidemiological study (the Mini-Finland Study, published in 1985) marked the beginning of a substantial re-evaluation of the scale of future needs; in others, a series of official reports contributed to the change.

## *Humanitarian*

There has emerged a general recognition that the *quality* of support provided in the past is no longer acceptable. Key developments here have been both professionally-led (for example, Health Advisory Service reports in the UK) and led by bodies more central to national political structures (for example, the 1991 Schopflin Commission report in France, and a 1988 National Health Council report in the Netherlands). Closely linked with these has been the growth of patients' and carers' representative groups, notably the Alzheimer's Disease Societies, and a growing articulation of the values and priorities of older people in general.

In many respects, developments in policy towards Alzheimer's patients and families reflect the development of broader health and social welfare policies for older people - the same policy drivers operate across all patient groups. However, different emphases and different conclusions have emerged to meet the particular circumstances of this group of people. Also, in many countries two somewhat separate policy 'streams' have converged to produce current policy: the framework developed for people with mental illness (with a particular emphasis on protection for those who are unable to safeguard their own affairs), and policies towards older people (with an emphasis on maintaining independence).

The principles which have emerged to underlie public policy can therefore be summarised as follows:

***Table 1: Key principles that have emerged to inform national policy frameworks***

Principles emphasised by all Member States	Principles emphasised by most Member States
1. People with dementia should be enabled to remain at home for as long as possible	1. There should be a systematic attempt to equate service provision with need
2. Carers should receive as much help as possible, in order to facilitate 1 above	2. Categorical care should be replaced by care which addresses the general needs of sufferers
3. Sufferers should retain maximum control over the support they receive	3. Early diagnosis of dementia should be encouraged
4. <u>All</u> relevant services should be co-ordinated at the local level	4. The needs of people with dementia are addressed only as part of the approach to older people in general at the national level
5. Sufferers in institutional care should live in surroundings which are as 'homely' as possible	



The rate of progress towards this consensus has varied between states. Some identified the needs of older and demented people relatively early, and others much later. Amongst the first to do so was France, where the 1962 Laroque Report emphasised the importance of 'extended domiciliary stay', and The Netherlands, where the 1963 First Law on Places for Elderly encouraged the development of domiciliary care. Other countries only started slowly to develop policy in the late 1960s and 1970s. During the course of the 1980s, however, the drivers identified above became much more pronounced, and policy development became much more rapid - the further development of policy in countries where progress had already been made, and initial stirrings in others (e.g. Catalonia, Spain from 1986, and Luxembourg, culminating in the governmental declaration of 1989). The result was that by the late 1980s, most countries were espousing the principles outlined above. However, in services for dementia, as in many other aspects of health and social care provision, the rate of development has been conditioned by the total amount of resources available for such services, with the result that in countries such as Greece and Portugal, both policy and service provision for this client group has developed slowly and rather later than in other member states.

The 1990s has been a period of consolidation, during which criticism has focused not only on the policy framework, but on the perceived inadequacies of its implementation. The fact of consensus on objectives does not, of course, imply that services and other policies actually ensure the desired standard of support in each member state. A number of criticisms of the implementation (or lack of implementation) of national policy have also emerged in most Member States. These highlighted areas where the espoused principles have not resulted in desired change because of:

- continuing lack of adequate resources, particularly resources 'ear-marked' specifically for this client group;
- the persistent relatively low status of dementia services in the broader context of healthcare;
- inadequate attempts to ensure patient and carer control of services, which remain largely shaped by organisational and professional imperatives;
- the health and social needs of patients and carers still do not always receive equal attention.

## The legislative framework

None of the Member States has enacted legislation relating to the specific needs and circumstances of people with dementia. Such people (and their carers) are therefore governed by legislation that attempts to address more generic situations.

Legislation falls into two main categories: that relating to the individual rights of people with dementia (much of which is written in the context of general mental illness); and that relating to the overall control of health and other services.

### *Individual Rights*

Legislation on individual rights shares several common assumptions across Europe, while of course reflecting the idiosyncrasies of different national legal systems. Such legislation is commonly relevant to the circumstances of individuals with dementia in the following cases:

- ***where matters of property require resolution*** - some states (e.g. The Netherlands, UK, Ireland) have specific provision for enduring powers of attorney, or ‘living wills’, which allow people to determine in advance how their property should be administered, and by whom, before they cease to be able to control it themselves; other states (e.g. Finland, France) do not have this provision, and seek to establish means of administering the property of demented people in a way which might best have met their wishes, once the dementia is established
- ***when giving consent to treatment*** - most states apply general mental health (and other) legislation where necessary to compel demented patients to receive treatment (under appropriate safeguards). Until that point is reached, however, many states enshrine in legislation the patient’s right to choose between different forms of treatment. In Finland, for example, mental health legislation is also available, but until patients qualify under that law, they have a statutory right under the 1992 Law on Patient’s Legal Status and Rights to care in accordance with their will, and if they refuse treatment or a particular procedure, they must be offered treatment in some other medically acceptable way. In France, individual rights are protected to the extent that a 1974 Statutory Order establishes the

patient's right of refusing hospitalisation, and a 1979 Code of Ethics states that consent is a juridical obligation which applies to all. In some States, however, (e.g. Luxembourg) specific legal guarantees of individual autonomy for dementing people are absent.

- ***when seeking access to medical and other records*** - many states have moved to provide certain rights of access to one's own (and a demented relative's) medical and other information: in Denmark, doctors are obliged to disclose a diagnosis of dementia to the patient.

Some states (e.g. Finland, UK) have also made statutory provision for patients' complaints procedures.

### ***Provision of services***

Legislation governing the provision of services takes three broad forms:

- ***permissive*** - agencies are empowered to act to meet certain needs, but the manner and extent to which they do so is left to their discretion;
- ***prescriptive*** - certain types of provision are required;
- ***regulatory*** - where certain types of service are provided, and the standards of that service are regulated by the law.

Most countries have a mixture of all three. In the UK, for example, health and social services authorities are often permitted to provide various general services, but are not *required* by the law to provide any more than a very loosely defined framework of care. However, this general obligation is supplemented by specific requirements under various Acts, for example to assess the circumstances of any carer providing substantial care on a regular basis, at that carer's request. There is also legislation which prescribes levels of welfare payment under varying circumstances. And then there is legislation to ensure that nursing and residential homes comply with an established system of regulation.

The extent to which the last category - regulation of service provision - has developed varies considerably between countries. Some of the most developed regulatory frameworks are

found in The Netherlands, where high standards of institutional residential care are enforced by law. The degree of legal prescription also varies considerably, from the rather loose situation in the UK and elsewhere, to the position, for example in Denmark, where state authorities are required by law to provide many specific services (e.g. home help, home nursing, and home nursing aids).

Some states – such as the UK - have more recently developed a legislative framework to ensure that the needs of carers are assessed (and, hopefully, met), and pressure groups in some other countries (e.g. Ireland) are pressing for similar provision.

## **The financial arrangements for continuing care**

‘Continuing care’ is defined here as being all forms of continuing personal or nursing care and associated domestic services for people who are unable to look after themselves without some degree of support, whether provided in their own homes, at a day centre, or in a residential or healthcare setting.

No country makes specific provision for the continuing care needs of Alzheimer’s sufferers. This can sometimes present problems, particularly when people have to qualify for support against general criteria – ‘being in need of permanent assistance and the care of another’ Those with early dementia can *appear* quite independent, but still need care.

In each of the Member States, a substantial proportion of the cost for continuing care is met by individuals themselves and their families (a recent estimate in France put the proportion at 57%). Each country has a different set of provisions for continuing care, all characterised by multiple sources of funding, and various eligibility criteria. The key dimensions, together with the range of different types of provision across Europe are identified in Table 2.

**Table 2: Key dimensions of continuing care and the types of provisions experienced across Europe**

Responsibility	Basis of provision	Needs addressed	Eligibility criteria	Form of support
<ul style="list-style-type: none"> <li>◆ Individual sufferer: <ul style="list-style-type: none"> <li>◆ Personal insurance</li> <li>◆ Co-payment</li> <li>◆ Full payment</li> </ul> </li> <li>◆ Family <ul style="list-style-type: none"> <li>◆ Part Payment</li> <li>◆ Full payment</li> </ul> </li> <li>◆ Insurance</li> <li>◆ Local government</li> <li>◆ National government</li> <li>◆ Charity/voluntary organisations</li> </ul>	<ul style="list-style-type: none"> <li>◆ Legal requirement</li> <li>◆ Discretionary</li> </ul>	<ul style="list-style-type: none"> <li>◆ Specific (e.g. housing)</li> <li>◆ General (e.g. income support)</li> </ul>	<ul style="list-style-type: none"> <li>◆ Means tested</li> <li>◆ Universal</li> </ul>	<ul style="list-style-type: none"> <li>◆ Cash</li> <li>◆ Services</li> </ul>

This complexity of each country's system frequently presents two problems. First, it can be difficult for individuals and families to understand (and therefore claim) their full entitlements. Second, disparities in entitlement between different local authorities and insurance arrangements, added to variations in uptake, can result in inequities in funding within Member States.

In most, the share of total expenditure borne by the state is under review. A common concern of policy in this area is to limit the future liabilities of the tax payer for the care of the elderly in general. This is being done by exploring various mechanisms of restricting entitlement to state-financed services (by imposing stricter needs assessment criteria, or raising thresholds under means testing), or increasing the element of individual co-payment.

### **To what extent are finances specifically targeted to this group?**

None of the Member States targets significant resources specifically at services for Alzheimer's Disease: the vast majority of provision is through generic services, either at the primary care/community level, or through more specialised services for the elderly or elderly mentally ill. As a result, precise estimates of the total quantum available for people with AD are generally not available, although research studies in several countries have revealed the

approximate balance of resources between categories of service provision. For example, Table 3 shows estimates from Denmark relating the number of people in different types of care with the total socio-economic costs for each category.

**Table 3: Estimated socio-economic costs of care for demented persons, Denmark, 1992**

Location of care	% of total demented persons	Estimated total socio-economic cost, 1992 (DKK bn)	% total socio-economic cost of demented persons
Own home	49%	1.8	23%
General nursing homes	39%	3.6	46%
Specialised institutions for the elderly	6%	0.7	9%
Psychiatric hospitals	3%	0.6	8%
General hospitals	3%	1.1	14%

Source: Felbo O, Lindahl J, Svarre-Christensen M, *et al* *Denentes vilkår: Hvad bør der gøres? En rapport om problemer, politiske målsætninger og initiativer på demensområdet*. København: Ældrepolitisk afdeling, Ældre Sagen, 1993

## What attempts are being made to address issues of equity?

For the purposes of this study, ‘equity’ was defined in terms of a mismatch between service provision and objectively assessed need for those services. The main dimensions of equity considered were:

- **access** to services - were the appropriate services available where they were most needed?
- **utilisation** of services - were those in greatest need actually receiving their appropriate share of the services available?
- **quality** of services - was the quality of available services matched to the needs of the people using them?

In each of the Member States, policy makers recognised the legitimacy of equity as a guiding principle, but it was accorded varying levels of priority. In some, such as Finland and Ireland, government policy explicitly states the importance of ensuring that use of services is

determined by need and not ability to pay, or geographical location. In others, such as the UK (at the time of writing) and France, the general requirement of universal provision was endorsed, although proactive attempts to reduce existing inequities were somewhat limited. In some member states, inequity is an inherent feature of the basic social support systems - in Greece, for example, people receive benefits from one of a large number of different social insurance funds, and the pension levels vary from under Ecu 80 per month to more than Ecu 800.

Across Europe, several common factors leading to inequity were identified by most governments. Geographical inequities tended to reflect four broad causes: basic differences in wealth and income between regions; historical patterns of unequal investment; the particular problems of providing adequate services in rural areas, where distance can be a powerful disincentive to service utilisation; and different policies and practices between local governmental and other agencies. At a fundamental level, several Member States were seeking to address basic socio-economic inequality, with a focus on macro-economic policy issues, as well as pensions provision and welfare support, both for individual sufferers and their carers. Many states were attempting to redress past patterns of unequal investment through targeted investment in service development in deprived areas. Countries with substantial rural populations generally sought to make special provision, in the form of some additional finance, to meet the needs, but usually not enough to satisfy the groups representing those people.

As far as differences in local policy and practice were concerned, many central governments were deploying a combination of exhortation to standardise, with increased central 'guidance' and regulation. Local authorities in some countries were themselves also seeking to improve standardisation between their various areas. In Denmark, for instance, the National Association of Local Authorities has recognised the problems which the lack of common definitions of need and service provision pose for inter-agency cooperation. As a result, they have taken the initiative to establish a 'common concept and common language' for the needs of the elderly in their localities, and the services provided for them. This should enable each authority to identify and analyse the needs of their clients, describe their efforts to meet those needs, make comparisons between themselves, and improve co-ordination of care with the health sector.

Most countries reported 'ageism' as one cause of inequity. Like most forms of discrimination, its impact was somewhat insidious, operating at both policy making/implementation levels and also at the point of interaction between service and client, and affecting all three dimensions of equity - access, utilisation and quality. For example, there was some evidence to suggest that comparable needs in the elderly population sometimes received less attention and resources than in younger age groups. Specific differences between the care provided for young and old victims of coronary artery disease has been described in the UK, and some countries also reported that a diagnosis of AD in the 'old elderly' often led to less attention from service providers than the same diagnosis in the 'young elderly'. In many countries, people diagnosed with dementia below the state retirement age were also entitled to greater social benefits than those diagnosed later - a larger disability pension, for example, which is denied to those in receipt of a retirement pension.

In those countries where there was a discernible shift in the balance of care from taxation-funding to individual responsibility, there were instances of resulting increases in inequity. In Finland, for example, there was some concern that the pressure to contain state expenditure on medicines could result in the poor being denied access in the future to medicines which might slow the progress of AD. In other countries, the policy drive to reduce state-provided hospital beds for the elderly could impact on those unable to obtain full support for private institutional care.

While most countries tended to focus on the 'access' dimension of inequity, others also sought to address inequity of 'utilisation'. Clearly there is a close link between the two, but in some circumstances the mere provision of services does not ensure that they are actually used by those in greatest need of them. This has led some states to make special provision for identifying and meeting the needs of the elderly, and if necessary, taking services to them. One example of this is the requirement in some states for the needs of all older people to be re-assessed on a regular basis. Another is the case of elderly immigrant populations, where language and cultural barriers can make existing service provision difficult to access, thereby compounding the high risks of social isolation inherent in such groups. Denmark, for example, is attempting to solve this problem by increasing the number of bi-cultural social and health care staff, and to make all staff aware of the particular circumstances and needs of refugees and immigrants.



## **How are WHO Health for All (HFA) policies being applied to Alzheimer's and neuro-degenerative diseases?**

Of the six broad themes within HFA, two (equity and multi-sectoral cooperation) are considered elsewhere, and one - health issues requiring international cooperation, such as pollution - is not relevant to AD. None of the remaining themes features prominently - or in most cases, at all - in member states' policies towards AD, and there is little evidence that national policies have been greatly influenced by HFA.

However, the WHO emphasis on health promotion, public involvement and primary care each finds its echo in national healthcare policies, and - inasmuch as they exist at all - in policies specifically addressing AD. Thus, many countries make explicit provision for health promotion for the elderly (although critics would claim insufficient provision, given the potential for *life-long* health promotion to improve the level of health of the elderly), and all are increasingly open to the advice of the burgeoning patients and carers' groups.

The official emphasis on primary care is evident in each country, although reflecting the difference in the organisation and structure of different healthcare systems. As far as AD is concerned, the reduction of long-stay hospital care for demented people has *de facto* increased the role of primary care, and most new service developments for this client group - regardless of their source of funding - are located in the community.

## **What targets have been set to improve health and social gain for elderly people with neuro-degenerative conditions?**

Two types of 'target' are evident in health and social policy development in the member states: specific policy aims related to the development of new or improved services (referred to here as *service targets*), and published intentions to achieve specified levels of health/social improvement (*health and social gain targets*). The majority of member states have not yet developed service targets which are relevant to the needs of elderly people with neuro-degenerative (ND) conditions, and none have developed a comprehensive set of health and social gain targets which adequately address the needs of elderly people in this situation.

Health and social gain targets are, notoriously difficult to develop for conditions where ‘cure’ is not usually a realistic objective. The two areas most commonly addressed in this regard - where services can realistically expect to make an impact - are personal care and the maintenance of human dignity. However, many observers argue that there is a dearth of reliable evidence relating to the effectiveness of many of the approaches and methods routinely adopted, and very little use made of systematic attempt to measure the impact on carers’ quality of life.

In addition to these generic problems that are associated with this client group, there are three common weaknesses associated with those targets which do exist. First, most states do not distinguish between the needs of elderly people generally and the specific needs of those with ND conditions: several states have developed targets for the elderly population, but the specific requirements of ND patients are not separately identified as objectives of public policy. There are some exceptions, however. In Ireland, for example, the recent *Healthy Ageing Strategy* has a goal to reduce the prevalence and severity of mental illness in older people and to raise the awareness of mental health issues. The action plans specific to dementia under this goal include continuing improvement in the treatment and control of hypertension in older people to reduce the risk of dementia associated with stroke, ensuring improved social and personal environments for people with dementia, and ensuring the burden of those who care at home for people with dementia is recognised and that their needs - for example in relation to support, training and respite and day care - are met.

Second, the targets are rarely quantified in a manner which would allow assessment of the extent to which they have been achieved. Two dimensions would be important here: a precise statement of the *amount* of change or improvement required, and a specific *time period* in which it is to be achieved. The UK has attempted to address this with a series of targets which specify the change required by a particular date. However, this approach has also been criticised, since the precise derivation of the numerical targets is often not clear, and it is often difficult to distinguish between changes which result from the implementation of policy and those which would have occurred anyway.

Third, the decentralised and fragmented nature of health and social care provision in many states makes the achievement of national targets very difficult. Several states have attempted to alleviate this problem by seeking agreement amongst the various regional and local

responsible bodies, but with mixed success. In Denmark, for example, local authorities are responsible for setting their own targets, and a recent investigation by the Ministry of Social Affairs concluded that 'management and collaborators' motivation is impeded by a lack of operational targets and an *ad hoc* follow-up often related to individual cases. The lack of targets means that there is no satisfactory basis for feedback. This is despite the fact that four years earlier the National Association of Local Authorities in Denmark promulgated some overall goals which could be applied to all older citizens in the country.

### **Inter-relationships with other aspects of social policy**

In each of the member states, several Ministries are involved in the provision of the different types of support for AD sufferers and their carers; and the situation is further complicated by the fact that both national and local/regional levels of government are also both involved. This results in every case in some degree of complexity of provision and therefore confusion for many of the people who are the intended beneficiaries of state assistance.

In practice, in most countries social workers or their equivalent play a crucial role for individual sufferers and their carers in identifying their potential entitlements and advising on appropriate ways of accessing them. There are also examples of successful attempts to coordinate the work of different national and regional government agencies with a responsibility in this area. For example, in Catalonia, the Department of Social Welfare and the Department of Health and Social Security work together to offer an integrated Quality of Life for the Aged Programme.

### **The role of national patients' and carers' organisations in informing national policy**

The growing influence of Alzheimer's organisations with the member states has paralleled the development of policy in this area. To some extent this reveals a cause and effect relationship - the growth of an advocacy movement has stimulated public policy - but also more generally reflects the growing strength of consumerism and of all patient/carers'

groups. In every state there is now at least one well-established national voice for Alzheimer's carers and patients. In countries with a longer tradition of cooperation and collaboration between government and other key stakeholders/service users - such as the Netherlands and the Scandinavian countries - the user groups are proportionately stronger and more influential; in other states - such as Greece and Portugal - the Alzheimer's societies are of much more recent origin, and have still to exert great influence at the policy-formulation stages.

All of the organisations have developed - or are in the process of developing - roles in the following areas:

- ***service provision*** - including caring services, and individual advice and advocacy facilities to ensure that carers and patients receive the services to which they are entitled;
- ***policy development*** - drawing in part of their experience as service providers, and also on the views of their members, organisations are to varying degrees consulted by governments, and seek to influence governments by overt lobbying;
- ***research*** – focusing on the needs of patients and carers, often with government funding.

Some concern has been voiced intermittently about the willingness of these organisations to champion the needs of sufferers when such needs occasionally come into conflict with those of carers. There has also been some concern that these organisations, dominated as they inevitably are by carers rather than sufferers, might occasionally advocate the needs of the carer more vigorously than those of the sufferer.

### **Anticipated developments in the next five years**

Two universal factors will drive change in the coming five years:

- increasing pressure on resources - the increasing numbers of older people generally will result in more people with Alzheimer's disease, at a time when all

states are concerned with containing the rising costs of welfare and other support for older people;

- demand for improvements in quality of services - especially from increasingly vocal and influential carers' organisations, demanding better quality of care for demented people and support for those who care for them.

Many countries will attempt to resolve these two policy problems simultaneously by encouraging acceptable quality care in the community. This is often perceived as being both more efficient (largely through the 'privatisation' of the responsibility of caring to the relatives) and of better quality (most people would apparently rather look after their ageing relatives themselves, provided that a reasonable level of support - in money and kind - is available to them). There will, therefore, be further de-institutionalisation of care, supplemented in many states by the provision of more, better-regulated nursing home provision for those people for whom informal care by relatives is no longer practicable.

These developments are generally welcomed, indeed demanded, by carers' organisations. Their chief concern is that the drive to contain costs will be at the expense of quality and quantity of service provision, and that the state and other collective bodies will not provide sufficient support to the newly-responsible carers.

Several other future policy themes will be important, but not in every state. Some countries, such as Ireland, will be reviewing their mental health legislation, to include an assessment of its relevance to the needs of demented older people. Others, such as France, will be considering the introduction of social welfare allowances and other measures specifically targeted at the needs of this group of people. In several countries, notably the Netherlands and the UK, there will be a continuing attempt to overcome the barriers to 'seamless' care which result from the different organisational responsibilities and accountabilities of those state and local agencies responsible for particular parts of the total care 'package'.

The policy context, then, is very mixed across Europe; and so, too, is service provision in response to the demands for services by people with AD and their carers, as the next chapter shows.

## **CHAPTER TWO**

### **CHALLENGES FOR CLINICAL PRACTICE IN DEMENTIA CARE ACROSS EUROPE**

#### **Introduction**

This chapter considers the issues emerging from Block 2 of Figure 1 – the identification and initial response to demand for services.

With the demographic shift and increasing proportion of elderly across Europe, it is predicted that the numbers of elderly people with dementia, and in particular Alzheimer's disease (AD) will double by the middle of the 21<sup>st</sup> century. Changes in the carer demographic profile and more women in the workforce also means that one can anticipate a decline in the number of informal carers available. Both of these changes occurring together will increase the seriousness of the care problem created by AD and other dementias unless there is a dramatic therapeutic breakthrough that either arrests or delays the progression of the disease.

Early, accurate and comprehensive diagnosis for all individuals suffering from Alzheimer's and other dementias is important. It gives patients the opportunity to take advantage of symptomatic treatments, allows them to make appropriate arrangements in advance of becoming incapable of doing so, and should have implications for access to appropriate services. Also, the failure to distinguish treatable disorders such as depression disguised as dementia, has serious implications for the patient and family.

In order to explore the challenges that confront the detection and diagnosis of Alzheimer's disease and other dementias, current clinical practice in Europe was examined. The Case Study Writers gathered qualitative data regarding the current state of clinical practice by interviewing key clinical personnel involved in this area. A list of topic areas was provided to each case writer in order to gather comparable information from each country (See Appendix 1). Published data on these areas were also identified and used to complete each country report. By necessity, much of the information gathered in this study is impressionistic and derived from 'expert' sources and therefore can only provide a general

overview of the situation in each country and across Europe as a whole.

By way of introduction, the level of development and sophistication of dementia care and the type and degree of specialist involvement is described for each country. The approach to detection and diagnosis in primary and secondary care and the issues surrounding disclosure of the diagnosis of dementia are examined. Finally, the topic of new treatments and prescribing practice was reviewed. Each of these represents a crucial element in the provision of a total package of care for sufferers and their carers.

## **The Development of Dementia Care in Europe**

Dementia care practice is at varying stages of development across Europe and can best be classified into four broad categories.

The descriptive categories used to compare countries are shown below.

***Table 4: Development of service for people with dementia***

Stage 1-Only basic dementia services available, if at all and those that do exist usually in general (psychiatric) facilities only

Stage 2-Separate and/or specialised geriatric programmes beginning to be established, including long-term care and community based

Stage3-Full range of long-term, hospital based and community based geriatric programmes exist in many parts of the country

Stage 4- Entire spectrum of services exist with multi-disciplinary teams involvement, hospital and community integration and co-operation throughout the country and equitable access to all in need

Using this system of classification, no country in Europe has achieved an ideal standard of dementia care and most countries are at the second stage of development. A number of countries including Sweden, Denmark, Finland and the UK have developed dementia care practices that have community, hospital and long-term care aspects. However, even in these countries, there are ongoing gaps in terms of liaison and co-operation between each of the

different component services. In Portugal, there are no specialised dementia care services, while in Greece, there are moves towards setting up some services for dementia patients. Other countries, such as Luxembourg and Belgium, have relatively few specific care services dedicated to elderly dementia patients. As a result, patients with dementia in those countries are included in the services for the elderly in general. Most countries in Europe are in transition stage and are beginning to develop specialised services. There is still considerable geographical inequity in those countries with services located primarily in urban areas. Only two countries have begun to provide specialised services for patients with pre-senile dementia - the UK and Germany.

In those Member States that appear to have more comprehensive dementia services, the issue of variation of service delivery within country has been recognised as a problem. For example, a change of policy in 1993 in Sweden, allowing municipalities greater discretion in the funding of services for elder care, has resulted in differences in service provision and eligibility criteria for dementia care between the municipalities. A similar inequity operates in Denmark but, as indicated earlier, an initiative, led by the National Association of Local Authorities, is underway to address this problem and to ensure the same quality in the services can be provided to the different geographical areas. In Ireland, while most health board areas have specialised geriatric services with assessment and continuing care components for dementia patients, only two health board areas have geriatric psychiatry services.

## **Specialists Involved in Dementia Care Across Europe**

The number and type of specialists involved in the assessment, diagnosis and treatment of dementia patients varies across Europe. It is helpful to consider the stage of development of specialists involved in dementia care according to whether there is accreditation or certification for that speciality in a particular country, and whether adequate numbers of specialists to meet needs. This enables a profiling and comparison to be made across Europe. The criteria used are shown below.



**Table 5: Degree of specialist involvement in dementia care**

1	No criteria for designation of old age psychiatrists, geriatricians, neurologists, community nurses - practitioners are self-designated
2	Accreditation/certification for the relevant specialties (geriatrics, old age psychiatry, neurology) exist and are well accepted by professional community and department of health
3	The estimated number of specialists in geriatrics and related specialties has been established but is not yet in place and gaps exist
4	Full complement of specialists sufficient to meet the needs of the country as a whole

Using this system, a number of findings emerged. Firstly, medicine for the elderly is a recognised speciality in all but two countries, Greece and Portugal. In other countries, including France and Luxembourg, although geriatricians provide a valued service, they are not recognised as a speciality and are self-designated. Surprisingly, geriatric psychiatry is recognised as a speciality in only one third of countries. Where the development of dementia care is in its early stages, there tends to be little or even no specialist development. However, in certain countries such as Sweden and Denmark, although there is no specialisation in geriatric psychiatry, there exists a highly specialised geriatric care system together with a relatively sophisticated level of dementia care.

The extent to which the different specialists are involved in dementia care also varies among the countries. For example, in Finland, Greece and Spain neurologists were predominant in terms of assessment of dementia in secondary care. In other countries, such as the UK and Ireland, geriatricians tend to see dementia cases with medical problems, old age psychiatrists see patients with behavioural and psychiatric problems, and neurologists assess primarily early onset cases. In Sweden and Denmark the bulk of assessments in secondary care are carried out by geriatricians.

Several countries have recognised the need to improve co-ordination between the different specialists involved in dementia care and between the different services available. In some countries a specialised service has evolved to address this. In Sweden the role and function of the Dementia Nurse can vary among the different municipalities, but in general terms he/she is the “personalised advocate” for the demented and their carers. In Denmark, municipalities are employing Dementia Co-ordinators, nurses with a special interest and training in dementia. A countrywide organisation in the Netherlands, The Riagg, with a

specific unit for the elderly, has a somewhat similar role.

With regard to the assessment tools and instruments used by secondary care specialists, throughout Europe, neurologists, geriatricians and old age psychiatrists, where they exist, are familiar with screening tools and standardised criteria for dementia. The most commonly used screening tool by specialists throughout Europe appears to be the Folstein Mini-Mental State Examination (MMSE).

## **Making the Diagnosis of Dementia in Primary Care**

Case study writers also examined how general practitioners (GPs) diagnose dementia, and whether they use screening tools. Different levels of assessment and diagnosis were identified and these categories are shown below.

***Table 6: Levels of assessment and diagnosis by general practitioners***

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|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ol style="list-style-type: none"><li>1. The diagnosis of dementia is not made routinely, no cognitive screening tests are used and national guidelines for primary care do not exist</li><li>2. Dementia is diagnosed based on symptoms and usually only when a problem arises; routine use of cognitive tests is not widely accepted; no sub typing occurs and either there are no national guidelines or if such guidelines exist they are not widely used.</li><li>3. The diagnosis of dementia based on symptoms and cognitive screening tests is used in many parts of the country, sub typing occurs, guidelines have been developed but are not widely used nation-wide.</li><li>4. The diagnosis of dementia based on symptoms and cognitive screening tests is used in many parts of the country, sub typing occurs and national guidelines exist and are widely used.</li></ol> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

In general, the level of detection in primary care is low across Europe. GPs tend to diagnose dementia based on symptoms only and do not use cognitive screening tools, guidelines or differentiate between vascular dementia and AD. GPs tend to see dementia patients late in the course of their illness, and only when they have a problem. Five countries (Ireland, UK, Holland, Finland, Germany) have guidelines for the diagnosis and management of dementia in primary care; and other countries, such as Belgium and Denmark, are in the process of

drafting protocols. However, studies carried out for example in the Netherlands and the UK, suggest the extent to which GPs use these guidelines is variable. Many of the country reports commented that younger patients were picked up and referred earlier and more frequently, suggesting an ageist bias in referral pattern. In Finland, for example, GP guidelines issued by one of the hospital districts recommend referral of patients under 70-75 and advise referring people over the age of 80 only under exceptional circumstances. 'Expert' sources in several countries indicated that younger patients were referred earlier from primary care, although there was no published evidence for this. In a number of countries, notably France and the UK, research shows a low rate of use of cognitive screening tools such as the MMSE. In Sweden and Denmark, it was noted that a significant number of patients were in contact with dementia services without a formal diagnosis by a doctor.

## **Disclosing the Diagnosis of Alzheimer's Disease**

Whilst the assessment and diagnostic methods used in secondary care differed very little between countries, there was considerable variation in the way in which the diagnosis was disclosed, and to whom. No country had guidelines on best practice in this regard. In Finland, Germany and Denmark, the doctor is legally required to inform the patient of the diagnosis; but although a patient's permission should be obtained in order to inform the family, this did not always occur in practice. In most countries, the doctor usually informs the family and sometimes the patient, depending on the stage of illness and the doctor's judgement in relation to the patient's capacity to understand the information. Clearly, with the availability of new treatments, early diagnosis will become more important and be demanded by the patient and family, and this may produce changes in disclosure practice.

Another important reason for making the diagnosis of Alzheimer's disease or the other dementias is the necessity of ensuring the interests of the individual are protected when he/she is no longer capable of doing so because of the illness. All countries have the option of guardianship proceedings, which are a part of general legislation but not specific for AD patients.

The advantage of diagnosis at an early stage is that it may allow patients the opportunity to

make an advance directive on decisions regarding their subsequent care and administration of their property, while they are still capable of making such decisions. Ireland, the UK, and the Netherlands are some of the countries where the facility of making such an advance directive exists. Sweden is considering introducing similar legislation at this time, and other countries have this type of provision, but only for matters of property and not for issues involving health and social care.

## **New Treatments for Alzheimer's Disease – How available are they?**

New drug treatments in the form of cholinesterase inhibitors have been licensed in all European countries. The availability of these treatments focuses attention on weaknesses in clinical practice in most countries, since they are often most appropriately used in the early stages of the disease, where there is a high level of certainty regarding the diagnosis. One of the findings from this study highlights the inadequacy of current practice in identifying this group. The issue of ageism mentioned earlier has serious consequences in this regard also. There is no evidence to suggest that those over 75 years respond any less well to these drugs than their younger counterparts, but the suggested bias against referring and/or diagnosing this group may affect their likelihood of receiving the medication.

The availability of these drugs for prescription by specialist or GP is not consistent throughout Europe. In some countries it is specialist only (e.g. Finland), in others the first prescription must be by a specialist (e.g. Italy, France), and in others again (Ireland, Sweden) any doctor can prescribe. Given the current state of expertise regarding the detection and diagnosis of dementia in primary care, the decision to allow GPs unrestricted prescribing of cholinesterase inhibitors would appear premature. However, issues of drug costs and budgets may have more to do with who prescribes than the level of clinical expertise and acumen. The availability and degree of reimbursement and the mechanism of this varies considerably throughout Europe and will be a major determining factor in the level of prescribing. In Finland one of the drugs in this class is partially reimbursed in common with other medications, while another is not reimbursed at all. In other countries, although the drugs are reimbursed, this is linked to a GP budget which will influence prescribing practice; and in some countries there is no mechanism for funding in place.

## **The Way Forward**

This part of the study has highlighted several gaps in clinical practice for patients with dementia. Across the member states there is variable specialist development with parallel gaps in dementia care services. In some countries – Portugal and Greece, for example - there is no specialist development for the provision of dementia care. In other countries, where the overall level of provision is higher – Denmark and Sweden, for example - there is an imbalance in the level of specialist development, which should also be examined. There is low detection and late referral in primary care and this seems to be uniform throughout Europe. Primary care physicians are poorly equipped to pick up early cases, and this is also a common trend across the member states. The lack of co-ordination for dementia sufferers across the different care levels was highlighted in many of the reports. Another issue is the bias against different age groups where older people may not be referred and younger people may be referred early although there are no services for this group in many of the European countries.

This examination of the clinical aspects of dementia care across Europe underlines both the challenge facing those involved in providing the care and the need to make changes. An increase in public awareness to improve the detection of mild cases is necessary as most often it is a family member or friend who first brings the patient to the doctor. Training and education at medical and nursing schools and at multidisciplinary level is important to increase awareness of the problem. At the primary care level there needs to be training and retraining with regard to dementia and the use of guidelines and of cognitive screening tests. There needs to be further development of specialists in secondary care and this will vary from country to country depending on where the gaps are. Co-ordination between and across primary and secondary care is extremely important and should be developed.

Having considered issues relating to the national policy framework, and the nature of clinical practice at the professional/patient interface, the next chapter considers the intermediate level – service provision at the more local level in Europe.

# **CHAPTER THREE**

## **SERVICE PROVISION FOR PEOPLE WITH ALZHEIMERS DISEASE AND THEIR CARERS ACROSS EUROPE**

### **Introduction**

In addition to gathering information on national policy and individual professional:patient interactions, the Case Study Writers approached a variety of sources to derive service information on the needs of individuals, evidence of staffing and other aspects of provision, as well as the social and cultural values that are inherent in dementia care. The results presented relate to Block 3 of Figure 1

Models of care are referred to throughout this section of the report. The new culture of dementia care operates in and through a clear commitment to human values. Service delivery decisions are made by careful consideration of how to compensate for the progressively deteriorating disabilities of dementia or how to supplement existing networks of support around the person in care practices in order to achieve equity overall. Responsive, flexible and adaptive services, with less hindrance from bureaucratic regimes and with fewer barriers to innovation, are the main aims of new care practices, involving the use of the care programme approach and multidisciplinary teams. Dementia Care Mapping, is an example of a person centred approach within the humanistic model of care for people with dementia.

### **Needs, Perceptions and Expectations**

**Are Alzheimer's-related needs of the population considered in each country, and if so by whom?**

The question of definition of need was raised in a number of reports. It was suggested that 'the concept of need is not well defined and has even been said to be underdeveloped', that 'need' is in fact an 'elusive' concept, and that 'estimates of need may vary considerably

depending on who is expressing them'. In order to develop a whole population approach, reported to be difficult in most countries, the UK report emphasises the 'importance of shared understanding of the term "need" in the introduction of a needs led approach to service delivery.

Whilst this principle has been identified, there appear to be a number of avenues followed for the consideration of population need. Some countries use a combination of means, usually based on epidemiological estimates, to identify need, while others report that there is no systematic approach to the specific consideration of the needs of people with Alzheimer's Disease.

The reported methods of consideration fall into a number of broad categories:-

- Identification and consideration of need through specific research and interested organisations, as in Denmark, e.g. the publication of reports related to dementia needs by the Association of County Councils in Denmark.
- Use of statutory and voluntary agencies to identify need. This method of identification consideration can vary greatly in terms dependant on who does the identifying and what influence agencies have in informing provision. In the Netherlands the government informs itself by instructing agencies to investigate the need of carers and patients, analysing results and making recommendations. The In-Country Report states that "according to the Alzheimer Society care is more and more adapted to needs, which agrees with the policy of government. Both statutory and voluntary bodies are effective".
- Using statistical information, Statistics Sweden provides epidemiological information and forecasts regarding the expected prevalence of dementia for each municipality.
- Extrapolation of information from a main system of mental health datasets. This appears to be the approach in many countries, such as Belgium, France, Austria. The Belgian report quotes 'Professional carers and policy makers often have the

opinion that people suffering from Alzheimer's disease cannot really be helped. As a consequence there are still elderly people in Flanders who are not well diagnosed and who don't receive the appropriate treatment'

- No consideration of Alzheimer's-related needs of the population. This is reported to be the case in Greece and Portugal; and in Ireland, The Alzheimer's Society is the only body in that country exclusively concerned with people with dementia and their carers and expresses a concern that there is 'no formal mechanism for assessing need'.

Despite these considerations there is very little evidence that, whilst research is growing and quantitative inputs are informing strategy, the specific needs of people suffering from Alzheimer's disease are being considered in everyday practice. Where they are considered it is predominantly from a service perspective rather than as a response to the needs of sufferers and carers.

## **How is demand for service predicted?**

As the assessment of need varies from country to country so does the manner in which prediction of service demand is made. Again the continuum of methods of service prediction range from structured to absent.

In many countries statistical data informs service prediction. In Denmark socio-demographic characteristics of elderly people in the population is used to predict the level of services required, and this is also inferred in other reports. Statistical data is a major source of information for Denmark, the UK and the Netherlands, but few reports state that dementia-related specific statistical information for service prediction is available.

Devolution of responsibilities to municipalities, communes and autonomous regions may create more transparent inequalities within geographical boundaries as each area may prioritise services differently. In many countries a national framework to maintain certain consistencies in service provision is often lacking. In Sweden, for example, only a small number of municipalities seem to have specific strategies for addressing the need of



Alzheimer's Disease, and in Spain regional healthcare planning shows no indicative prediction for Alzheimer's related disorders.

Service prediction by demand is characterised in the Luxembourg report with figures drawn from 'foreign' studies. Prediction in Greece is based on the very limited numbers attending memory clinics or neurology departments.

The information received suggests, therefore, that prediction of services for people with Alzheimer's and related disorders is poor. Where information is gathered it is part of a global picture of the provision of service for older people. Specific state centralised predictions can be lost in the transference to local application as decentralisation creates more autonomy at local level with fewer resources available to fund epidemiological activity. Information from insurance based systems, as exists in Germany and France, is financially biased and not considered a true predictor of demand. Payment loss by G.Ps in Germany who refer the person on to secondary services, for instance, may result in delayed referral or non-referral to specialist services.

### **Are the needs of carers incorporated?**

There has been some consideration of the needs of carers, but the amount and appropriateness of this consideration is questioned. In Sweden there have been policy statements since the 1980s, and there has been recent legislation in the UK in the form of the 1995 Carers (Recognition & Services) Act, and in Ireland, the Carers Charter. In most of the Member States, the needs of carers are considered in a similar way to those of people suffering from dementia, through research by interested organisations, particularly the Alzheimer's Associations. There is no general assessment of the needs of carers on a national level in Finland or in France and no specific recognition of the needs of carers who assume responsibility for patients affected by AD.

There is a widespread call for a more integrated approach to meeting the needs of carers and a recognition that there are dramatic differences in the process of caring for individuals with Alzheimer's disease and related disorders. In Ireland, recommendations made by O'Connor and Ruddle (1988) reflect emerging principles for carers inferred in most country reports:

- Support services should be varied and flexible, and should be orientated toward the specific needs of the carer, and responsive to the changing nature of the caring role;
- and
- Health boards should be restructured to include carers in planning and provision of services, to incorporate them into a definitive policy of partnership in caring.

## **How is Alzheimer's Disease perceived by the public?**

Characteristic views of the elderly population are influenced by different cultural and societal beliefs. The public perception of Alzheimer's depends on factors such as:

- Well developed research in the field giving rise to public debate;
- Media representations of Alzheimer's and related disorders;
- Active interest groups and Alzheimer's Societies;
- Stigmatisation of the disease.

There is a growing awareness of the AD generally, but, particularly in those countries with well established and active Alzheimer's organisations. It is possible that there is a link between the length of time Alzheimer's organisations have existed in the country and levels of public awareness. Member States where there is a greater advancement in strategic thinking and more central involvement in policy formulation report a higher level of public awareness. An overwhelmingly negative view of older people in general is accompanied by less public awareness and more stigmatisation in relation to dementia across all age groups of sufferers.

## **Does government policy imply an expectation that families will care?**

The traditional model of care follows the nuclear family system, with elderly people forming an outer circle and attempting to remain independent and maintain personal privacy for as long as possible. A number of member states have expressed commitment to public responsibility to care and most European policies support community care for older people.

There appears to be a high degree of inequity in the type of state support offered, and a direct correlation between low state support and high family responsibility. In Finland and Denmark, familial responsibility for care is specifically excluded: 'the formal duty of children to support their parents was deleted from Finnish Law in 1970'. In Denmark: 'It is stated that the family is under no obligation to look after an elderly parent'. In present policy statements the Swedish Government has 'repeatedly stated that it is a public responsibility to provide the elderly with necessary housing services and care according to need'.

By contrast, in Greece, the stigma attached to placing elderly people in homes gives licence to the state expectations that families will care and the case report suggests that 'the state sector in the field of social service in Greece assumes a residual role. It is mainly aimed at filling the gaps left by the family'.

Although care in the community is explicit in some government health policies, such as in the UK and The Netherlands, there is still a tacit expectation that families will care. The majority of reports state that whilst it is policy that older people are maintained in their own homes for as long as possible, there is an expectation that families will care. There are a number of reasons for this, the prohibitive cost of long term institutional care being a major consideration. The main stated aim of many countries' government policy is for domiciliary care, with support and alternative services to institutionalisation being provided. The issues surrounding the humanity or otherwise of institutionalisation are seldom directly expressed in policy terms but a movement towards greater use of nursing and residential care for people with dementia seems to be one of the effects in services of improved recognition of carers' needs. This reflects a limited view of what carers are in fact asking for, as identified in the reports for this study.

## **Current Service Provision**

### **How are clinical and/or social services allocated?**

Clinical and social services are allocated in a number of ways:

- **Allocation of Care by Need** - Denmark demonstrates a social welfare model based on taxation. Characteristics are easy access and extensive provision. All citizens are guaranteed fundamental rights to healthcare.
- **Allocation by Need with some Charges** - Costs payable for either social or health services. In the UK there are some charges for social services; in Sweden some fees are payable related to income; and in Finland there is a charge for GP visits.
- **Means Tested Health Care** - Limited eligibility for health care services based on income, or social services are means tested as in Ireland.
- **Compulsory Social Insurance** - Austria and Belgium have forms of compulsory social insurance. Payment for care services are again according to income.
- **Personal Health Insurance** - Private Health Plans to cover health service needs. In Germany there is some means tested provision for residential/nursing home care. In Luxembourg there is a means tested safety net; however, medical expenses are not completely covered by insurance, except for chronic illness, and AD is not considered chronic health problem.
- **No Mechanism for Service Allocation** - This appears to be the case in Greece and Portugal.

## **To what extent is the non-statutory sector involved with service provision?**

With one exception there is a reported growth in the investment in the care of the elderly and private retirement homes. In Denmark, however, the overall impression from international surveys is that: 'Denmark is the only country reporting such extensive municipal services that help from family and private organisations plays only a minor role' (EF Kommissionen 1991), and that 'the non statutory sector is practically non existent in Denmark'.

In other countries the private segment of the nursing home market has increased significantly. This growth is occurring as home care is encouraged because of financial constraints, statutory provision is reduced, and an increasing number of people need care. Increasing the importance and involvement of the private sector in service provision, whilst at the same time raising questions about the differences in quality of provision for people with Alzheimers and other related conditions, is a concern in most countries. In France, this sector is 'poorly developed'. In the UK: 'one of the greatest difficulties in analysing the proportions of statutory and non statutory service provision in health and social care throughout the country is that there is little uniformity in the nature of services delivered or the resources available'. In Sweden 'it is not known to what extent private contractors are used to provide nursing and care for people with AD.'

The importance of the under-resourced voluntary organisations and independent charities has also increased. Alzheimer's Societies have grown and organisations such as Crossroads in the UK and the Working Group for Family Care Givers in Flanders have developed. Reports show that non-statutory provision is crucial in the care of people with AD and their domiciliary carers. The lack of readily available documentary evidence about this sector at the national level in most countries is a worrying sign that services cannot be as well co-ordinated across all agencies as the vast majority of stated national policies imply. This leads to gaps in crucial mental health care-planning procedures which have been the subject of media attention in many Member States.

## **What support is available to family care-givers?**

Formal support services for carers appear to be sporadic, no overall packages of help for carers are evident, and it is universally agreed that the understanding of care givers needs is inadequate. Many services to carers of people with dementia are not specific to the condition but included in services to carers of people with other needs and are, therefore, not always comprehensive or appropriate. Voluntary organisations are finding themselves with a growing responsibility to attend to the needs of carers. Support offered to care givers falls into three main categories - financial, respite and counselling/personal support:-

- Financial support is available in the form of direct payments to carers and varies within countries. In some rare instances, government funding is available for individuals to take time from work in order to care, but in the majority of Member States there is little or no financial state contribution.
- Respite care is equally variable and there is little uniformity between countries.
- Emotional support is reported to be usually provided by voluntary organisations.

The Alzheimer's Societies are now active in all countries to some degree, although less so in the more economically deprived countries. The degree of support and information carers receive shows some correlation between the number of branches of the Alzheimer's Society and the length of time they have existed in each country. Despite this and the growing number of carers groups, there is still a limited amount of respite, emotional support and information available to carers. Psychological and emotional support is not a statutory requirement, although its importance has been recognised for a number of years. There is some evidence to indicate a trend towards formal recognition, e.g. in the UK Carers Act and in the public social protection offered in Finland. However, help is reported in general to be sporadic and unstructured.

## **Who makes up the main workforce?**

### *Informal Carers*

The majority of people working with AD sufferers, and those with related conditions, are reported to be informal domiciliary carers usually family, friends or neighbours and existing community networks. Reports indicate that approximately 80% of people with such conditions are cared for by informal, unpaid, mainly female carers across most countries.

### *Voluntary Members of Organisations*

Voluntary organisations are supporting informal carers in their work by offering some social services and respite care. They comprise a mainly female workforce, with no paid employment.

### *Home Helpers*

There are different understandings of the definition of home helper - in some cases they provide only domestic help, in others some personal and limited medical support. In Sweden the orientation is towards health rather than social care. By contrast, in the UK, the emphasis is more toward social care. Home helpers usually work part time, have little to no formal training, are poorly paid and are mainly female. They are reported as the main paid workforce in the care of people with AD.

### *Carers in Care Homes*

Paid unskilled care workers provide care in formal residential and nursing home settings, but of varying Quality and as such are causes of concern in many countries.

### *Visiting Nurses/Home Nurses*

Professional nursing staff have limited responsibility for people with AD and there is a widely reported 'under investment in training, support and supervision for nursing staff in this field.'

### *Formal Care*

It is difficult to assess the specific number of professionals working with dementia. Many countries report that there are some community based services which differ in type and

access. In Denmark there is “extensive professional involvement” and in Ireland “limited community based services”. Breakdown of professional involvement in service provision for people with Alzheimer’s is also difficult as provision is often included in other elderly care.

Estimates of the formal workforce suggest that between 75% and 95% are female.

### **Are there any qualifications or training for paid care-givers?**

All professionals working in the field have specialised training, but not necessarily in dementia care. It is suggested that this is due to there being a general lack of professional interest in elderly care. Qualifications exist in formal services but are severely limited in informal and voluntary care. There is no uniform structure of training and qualifications for paid care givers within the Union. Various organisations have, however, pressed for such training.

### **Professional involvement in service provision.**

Although there is some difficulty in assessing the degree of professional involvement in the care of people with AD, an identification of a range of health and social care workers was made. Key professional involvement was through:

- General Practitioners
- Community Psychiatric Nurses
- Practice/District Nurse
- Health Visitors
- Social Workers
- Old Age Psychiatry Services
- Geriatricians
- Psychiatrists
- Neurologists
- Other Therapists



Some nursing and other institutional care homes offer professional services, some medical and/or social care at day clinic and rehabilitation centres. There are a limited number of specialist centres for people suffering from AD, and where they do exist they are reported not to be accessible to the whole population for a number of reasons including financial constraints and geographical factors. There is a fairly wide network of memory clinics in the UK and Germany, and this development is increasing elsewhere such as in Austria.

### **What is the balance of specialist and non specialist facilities?**

The majority of people with dementia are living in their own homes - 69% according to the Alzheimer Europe. There is little evidence of specialist dementia care in nursing homes and domiciliary care services; and so it would have to be assumed that the balance is towards the majority of facilities being non-specialist. In the UK, nursing homes which are dually registered to include people with mental illness, are seen to provide one form of appropriate specialist care for elderly people with dementia. Where such specialist facilities are used for people with dementia, they are unlikely to be used to enact legislation to detain people at risk. It is informally reported that specialist facilities are required to attract staff with the qualifications, skills and experience required to deliver care to a group with highly complex and challenging needs. As in services to other challenging groups, however, the availability of such staff is severely limited and forms the subject of several critical national reports.

In summary, many countries do not have specialist facilities for people with AD or specialist out-patient provision. Some countries state that there are specialist units in hospitals, e.g. Denmark, UK and Germany, but in general the more affluent countries are making the eligibility criteria more stringent for people with dementia to receive continuing care in hospital. Luxembourg is unusual in that psychogeriatric wards in nursing homes are specifically referenced. The balance of services can also change within boundaries between different municipalities, communes and regions.

## **Type and availability of programmes and treatment of care.**

The type and availability of programmes and treatment of care is very divergent across the EU. Some countries have been heavily reliant on health care assessment and treatment programmes which may have moved into the community; and others have developed a model of treatment which is predominantly social care based with medical and other health care inputs. Disadvantages of both extremes are described in the reports and the ideal model (a true partnership of health and social care) is almost universally agreed, yet seldom achieved.

The following range of services was identified by the Case Study Reports:

***Table 7 Elements of service provision***

Home Care Service	Domestic support, domiciliary nursing, auxiliary nursing
Primary Care Teams	General practitioner, nurse, therapist, assessment and care planning
Social Care	Social workers, assessment and care planning
Day Care	Support worker in own home, social care, hospital-based (decreasing)
Respite Care	In own home, unit/centre
Secondary Service	Psychogeriatrician, geriatrician, neurologist
Nursing Homes	For-profit, charitable
Hospitals	Psychiatric units, geriatric and general
Residential Homes	State (decreasing), for-profit, voluntary, religious
Voluntary Sector	Domiciliary, support workers in own home

The main focus for provision of the initial assessment and service contact is co-ordinated at different points in the primary/secondary interface across countries but is generally moving in the direction of increasing involvement by primary care. Finland is probably the most extreme example of a primary care led service for people with dementia. The main criticism of this approach is that insufficient attention is paid to specialist diagnosis and treatment. Greece and Portugal provide the most extreme examples of services centred on the family and only last-resort availability of traditional institutional care for those in greatest need or without families.

## **What are the discrepancies between national and local policies?**

Where there are national policies that exist to influence services to people with Alzheimer's disease it is widely reported that the devolution of policy to local levels is problematic. The UK report states that:

“Mandatory legislation is often couched in very broad terms which leaves wide scope for local interpretation”.

In Luxembourg, differences occur for rural populations; and some countries report autonomous regional controls, as in Spain and Italy, which influence the implementation of national policy and develop separate systems to some extent. Denmark, Finland and Austria report differences between municipalities and communes.

## **Can service users and carers influence future service developments?**

There is a reported growth in carer movements across the European Union. Certainly countries with strong Alzheimer's Societies and other lobbying organisations are developing strategies to make known the needs of carers. The development of community and primary care and the interaction between statutory authorities and the voluntary sector could see a rise in the influence of service users and carers. The lack of provision and support, in general, for service users and carers seems to indicate that they have little real influence at present. In this respect the rhetoric of most national policies is not matched by allocation of resources.

## **How are Alzheimer's-related service funding priorities established?**

There is evidence that the care of the elderly is high on the agenda in a number of member states. There is, however, little to suggest that Alzheimer's related service funding priorities are being established. Dementia services are encompassed within other mental health services or within services to older people generally. Targets have been established for a more effective use of resources in many countries but these are not generally reported to establish Alzheimer's Disease as a priority, although local regions in devolved health care systems do establish their own priorities towards older people or mental health.

## **How are future service plans influenced by Alzheimer's related research?**

Although research is being carried out, in general it was reported that there is no evidence of a formal influence on service plans of findings from Alzheimer's related research, and that there is a gap between research findings and practical application. In Ireland and Finland it is reported that a major interest is in the work on the development of new medications. Luxembourg is seen to be too small to undertake specific research, but consideration is taken of other European research findings. At the national level in most countries international research findings are considered; however, at local levels, the work appears to have little influence.

## **What happens to people with Alzheimer's and related disorders not in contact with specialist services?**

People having no contact with specialist services are cared for at home and in the community, usually by members of the family or in non-specialist private nursing homes. The explanations for this are cultural – related to the stigmatisation of the condition - or economic, resulting in a lack of facilities and state support. Even though it is recognised that quality of care has improved overall in recent years and there have been many positive developments - notably a number of pilot projects of new and innovative services led by dedicated staff teams - it is also broadly reported that people with dementia in non-specialist care have a poorer quality of life.

## **The Way Forward**

Clearly, there are many examples of a failure to implement at the local level the principles of good quality service provision which are espoused by policy makers and most professional organisations in each of the Member States. There are several encouraging signs for the future, however, perhaps the most important of which is that there is a considerable consensus on many of the *desiderata* of service provision. The challenge now is to overcome the gaps between theory and practice, and this challenge is addressed in the final chapter.

## **CHAPTER FOUR**

### **CONCLUSIONS AND RECOMMENDATIONS**

Much of the data presented earlier in this report will be of interest to individual Member States, and to particular interest groups within Europe as they measure progress within their own countries. The purpose of this final chapter, though, is to highlight the issues which the authors consider to be of *greatest significance for the Union as a whole*, and to offer concrete proposals to improve the well-being of people with Alzheimer's disease and their carers in Europe. As always with such summaries, the selection will to some extent be personal, or even arbitrary, and policy makers and practitioners are also urged to draw their own priority lists of recommendations from the rest of the report.

#### **KEY ISSUES**

##### **AD sufferers and their carers are treated inequitably by Member States**

The whole context of policy relating to Alzheimer's Disease is characterised by paradox. On the one hand, there is general recognition that people with the condition (and other dementias) receive a generally poor level of service in comparison with other groups; and yet, on the other hand, there is little sign of impending large-scale improvement. It is upon an understanding of the reasons for this paradox that future progress depends, and part of the answer lies in the low status accorded to this group of people.

Although the Member States differ considerably in terms of their policies and services for people with Alzheimer's Disease and dementia generally, it remains the case that every state accords this client group relatively low status. There are many indicators of this, such as the absence of planning processes and policies specifically targeted at this group, the relatively low prestige enjoyed by many doctors, nurses and other healthcare professionals working with demented patients, and the ambivalent nature - bordering on social stigma - typical of

much popular media coverage of dementia, both fact and fiction. This low status underlies many of the other issues described below.

The causes are many and various. They include:

- the lack of good models of service provision from the past - partly because dementia has only relatively recently become a major public policy issues as the population has aged;
- the low prospects of cure for most patients, which tends to conflict with the medical (and other health professionals') overriding aim to save life;
- the often ambiguous attitude of society at large to its older members - a complex mixture of respect, love and sympathy, coupled with contempt, fear and lack of understanding;
- the 'invisibility' of the problem, in part a consequence of the marginalised position of most patients, effectively denied a public voice by the consequences of their condition;
- the willingness - at least hitherto - of most families of people with dementia to arrange for the care of the affected relative without demanding more resources;
- the concern of Ministries of Finance and insurance companies that the burgeoning numbers of demented people, coupled with the low level of historical provision for them, might lead to an explosion of demand for services which could not easily be afforded.

Many of the above are, of course, inter-related.

The proportion of professional staff specialising in dementia shows a high degree of national variation which appears to be related to the level of economic development of the country. In all countries, however, most of the staff caring for people with AD and related disorders, whether in domiciliary or residential/nursing settings, are untrained and poorly supervised. They are generally regarded as of low status, despite the numerous challenges of their work, and recruitment is difficult. Most of the workforce is unqualified nurses, care-workers or

members of charitable and religious organisations. Staffing ratios are often unfavourable, yet there is known to be a considerable degree of ‘burn-out’ in working with people with high levels of mental and physical dependency.

Identifying a community of interest in relation to people with AD and related disorders from a national perspective has proved to be a challenge in itself. The AD Disease Societies came closest to playing this role. If one compares this situation with the community of interest around people with learning disabilities, for example, where in many countries a number of stakeholders have developed a common set of demands, dementia is still a long way behind. A community of interest encourages an ongoing examination of how values related to the group in question are upheld in services. The formation of a community of interest generally occurs when groups of people with disabilities are more formally acknowledged. The reported lack of specific AD policies, together with general concerns that the growing numbers of sufferers will be overwhelming, may well be related to this finding.

**Recommendation 1** *There should be a concerted attempt, both at national and European levels, to use the most effective means of public education to change negative attitudes towards AD, and in particular to emphasise the benefits to be derived from early diagnosis.*

**Recommendation 2** *Member states should use whatever policy levers they have available to them to increase the professional status of healthcare staff working with demented patients, and professional bodies themselves should develop strategies to achieve the same ends.*

**Recommendation 3** *As part of the strategy to raise the status of AD services, member states should encourage the development of local, regional and national ‘communities of interest’ for AD which bring together all the relevant stakeholders. The Commission should consider providing a degree of European co-ordination to such efforts.*

## **There is inequity within and between Member States in dealing with Alzheimer's Disease**

It is often difficult to compare the quality of health care provision across Europe, given the very different organisational and philosophical contexts in which the Member States work. In the case of AD, however, such comparisons are made somewhat easier by the fact that there is such a high degree of agreement on the basic characteristics of good policy and service provision. It is possible, therefore, to map the extent to which individual member states fall short of the ideal.

There are many examples of inequity of provision of dementia care across the different member states of the EU. Clinical practice models are quite advanced in some countries but are embryonic and at an early stage of development in others. Even in those countries where dementia care practice is well developed, there is often geographical inequity in the provision of such services in these countries, or imbalances in the level of specialist provision that translate into inequity for the sufferers and their carers. In most member states, primary care personnel are significantly under-trained and under-resourced to deal with the rising tide of dementia sufferers, contributing to the late detection and treatment of these disorders.

Funding mechanisms, drug re-imbursement procedures and prescribing for new drug treatments in Alzheimer's disease vary from country to country and represent another source of inequity for patients and their carers. Alzheimer's disease and dementia are unique among the leading causes of chronic disability and ill health in that the sufferers themselves are often not able to act as advocates for the treatment of their condition. This may partly account for the low priority given in some member states to the funding of new treatments and interventions for this condition.

The degree of standardisation of service responses to AD also varies between countries. For example, the same clinical presentation may lead to a referral to support services in one region but not in another part of the same country. The reasons for this seem to be less to do with the financial systems involved in paying for health and social care and more related to the process of interpretation of national policy into priorities at local level. For those countries where needs had been estimated, the Case Study Writers frequently commented on



the difficulty of the task, particularly in the absence of a consensus around definitions of AD and related disorders. International and national studies provided estimates of prevalence, although it was rarely possible to estimate incidence. There is widespread concern about the process of interpreting when a dementing illness constitutes a need, especially a health need. Countries with policies of universal access to health care are especially concerned about how to meet increasing demand as a result of demographic changes and the licensing of new medications.

No state has a perfect level of provision, and there is room for improvement in all. It is also true, however, that some have managed to develop better provision than others. This is often explained by such basic issues as the strength of the local economy (as a key determinant of the level of expenditure on welfare); but whatever the cause, there is a clear *prime facie* need for co-ordination of services and policies to reduce current inequities.

**Recommendation 4** *The Commission should work with Member States to provide assistance to those whose services for AD are furthest from the ideal level of provision.*

**Recommendation 5** *Member states should review (and where necessary improve) the consistency of local application of nationally-accepted and Community-wide good practice in relation to AD.*

## **Intervention often occurs at too late a stage in the progress of Alzheimer's Disease**

The intellectual and humanitarian case for early identification of people with AD is by now well established. And yet, many policy-making organisations, as well as individual practitioners, still do not accept the case; or if they do, they seem unable or unwilling to bring it about. This is partly a consequence of the generally low status of AD. But there are also more specific causes. Many professionals lack the relevant skills or time to perform the differential diagnosis necessary, or can see little point in so doing, given their orientation towards saving lives. There may also be argument that the patient's best interests - in terms of preserving their dignity or confidentiality - are not served by making an early diagnosis. Relatives, too, will often collude with professionals and request that the diagnosis not be

disclosed to the patient, further underscoring family members' negative attitudes to Alzheimer's disease.

**Recommendation 6** *The relevant agencies in each Member State should develop an effective strategy to increase the level and quality of assessment and diagnosis of AD at the early stages of the disease, and should consider setting targets to this end.*

**Recommendation 7** *Each Member State should also ensure that general medical and allied professional education includes sufficient input on dementia at undergraduate, postgraduate and continuing education levels.*

## **Alzheimer's Disease Policy should be co-ordinated, and services multidisciplinary**

Service provision provides the ultimate test of policy integrity. A lack of specific recognition of AD and related disorders was reported across the EU despite considerable growth in the carers' movement generally, and that the social consequences of cognitive impairment have been highlighted.

AD patients have a multiplicity of different, and often quite intractable, problems. There is much attention paid now to the need for multi-disciplinary health and social care, and for the application of both medical and social models of care - and nowhere is this more needed than in the case of services for people with AD. A whole range of professional disciplines must be brought to bear at the appropriate junctures, including (where they exist) General Practitioners, Community Psychiatric Nurses, Domiciliary Nurses, Health Visitors/Public Health nurses, Social Workers, Old Age Psychiatry Services, Geriatricians, Psychiatrists, Neurologists, and other therapists. It is not that multi-agency dementia services do not exist, but that policies frequently do not support their development or continuation, and other priority groups take precedence. The literature is abundant with good demonstration projects for dementia services in a number of countries, but our investigation so far indicates that they have not had a pronounced impact on policy.

Particular problems were revealed in generating preventive approaches for the *social* consequences of cognitive impairment in elderly people - a failure to take account of the uniqueness of a dementing illness like AD, is how one respondent put it. Multi-agency working can greatly improve the prospect of the totality of the patient's needs being properly addressed.

The best match of service to need will often be achieved by addressing the issue of appropriate specialisation. All European health care systems depend to some extent upon generalist professionals identifying the healthcare needs of the population, and meeting most of those needs themselves. In the case of AD, generalists must be able and willing to perform the majority of assessments, and to provide continuity of care to the patient and their carers through the progression of their disease. If they are to fulfil this role effectively, however, they must also have easy access to the sorts of specialist services which it would not be practicable to provide at the primary care level. Deficiencies in both sectors must be addressed simultaneously. Policies directed towards co-ordinating services through a form of primary care, together with social care planning and defined pathways into secondary specialist services, are particularly important for the future direction of services.

At present it is relatively uncommon for institutional services to deliver individualised care irrespective of the level of severity of the person's problems. If most staff providing direct care are untrained in the effects of dementia, there is a tendency to believe, in line with popular misconception, that the difficult behaviour often displayed by people with dementia is deliberate. Such beliefs are associated with dehumanising care practices. In Member States where the balance is still towards large scale institutional care, there is a case for making institutional care the last resort when all other attempts to support the person through formal services in their own home have failed.

Policy makers, too, need to work across boundaries for this particular group of people. In fact, most government departments formulate and implement policy which can improve - or make more difficult - the lives of people with AD and their carers. Such departments include social security, transport, and housing, as well as the more obvious health and social services sectors. Most Member States have examples of where policy formulated for another group - such as those with physical disabilities - is being applied to the circumstances of those with dementia, with the inevitable results. What is needed is policy specifically formulated to

meet the unique circumstances of dementia, and which embraces all relevant departments and agencies.

Again, one returns to the issue of priorities: co-ordination could be achieved, if only it were accorded sufficient priority amongst policy-makers and service providers. The pre-existing boundaries, which make little sense from the perspective of AD patients and their carers, usually serve other - valid - administrative purposes. Therefore the objective should be either to develop mechanisms for bridging the divides in this instance, or to create entirely new arrangements for patients with dementia. The preferred option will depend upon the individual local circumstances, but the degree of priority should universally be high.

It would also help national governments if there were more effective means of disseminating through Europe the lessons of practice development and models of organisation in individual countries.

**Recommendation 8** *Member States should continue to address the need to improve co-ordination - at the policy and implementation levels - to meet the total needs of AD patients and their carers.*

**Recommendation 9** *The balance between generalist and specialist provision should be revised in each Member State, in order to ensure that both are fulfilling their most appropriate roles.*

**Recommendation 10** *A mechanism should be established to evaluate and disseminate across Europe new models of service delivery and organisation.*

## **Carers of Alzheimer sufferers require better support**

The support available to family caregivers is widely reported to be inadequate, despite the evidence of effectiveness of several psycho-educational approaches with informal carers. In some of the more economically deprived countries, families perform the majority of care in the absence of alternatives, and without explicit consideration of the emotional costs to both sufferer and carer of the consequences of such a policy. In other member states, family carers have the right to apply for support or to request an assessment of their needs. The

disincentives to applying for support of a financial, practical or emotional nature are reported to be high in most countries which make provision for informal carers. The impression is also given that despite the Alzheimer's Disease Societies actively performing the role of carers' pressure groups, little carer participation in service planning takes place.

Research evidence indicates that the carers of elderly people with dementia have poorer physical and emotional health than carers of elderly people who are equally dependent but less affected by deteriorating mental capacity. Also, a higher proportion of family-caring situations break down irretrievably when the carer of an elderly person with dementia becomes unwell themselves for a period of time. Frequently the crisis response of services is less effective in maintaining the person with dementia than is the family care-giver, and this is even true of elderly spouse carers. It is very much in the best interests of services to support any existing carers before they cease to be able to cope.

**Recommendation 11** *There should be further improvements in the systematic identification of the needs of carers, supported by the allocation of adequate resources to meet their (often modest) requirements.*

**Recommendation 12** *All Member States should continue to improve the mechanisms used to involve care-givers in the planning of services.*

This report identifies a substantial a check list for policy makers at the European, national and local levels. In most instances, the research has revealed enough to enable policy makers to start to act now. But more work would greatly facilitate this process, and the European Commission has already funded a further phase of projects to enable this to happen.

## References

- A Handbook on the Mental Health of People, Health of the Nation*, Department of Health, Yorkshire, (1997).
- Biggs S, *Elder Abuse in Perspective*. OU Press, (1995).
- Burns A, Jacoby R, Levy R, Brit. J *Psychiatric phenomena in Alzheimer's Disease*. 1. *Disorder of thought content*. Brit. J Psychiat 157, 76-81 (1990).
- Cutting J., *The phenomenology of acute organic psychosis* Brit. J. Psychiat. 151, 324-332, (1987).
- Drevets W.C. and Ruben E.H., *Psychotic symptoms and the longitudinal course of senile dementia of the Alzheimer type* Biol. Psychiat 25, 39-48, (1989).
- EF Kommissionen. *First Annual Report of the European Community Observatory*, June 1991, EF Kommissionen, (1991).
- Forstl H, Osvaldo P, Iaconi A & E, *Capgras delusion in the elderly: The evidence for a possible organic origin*. Int. Journal of Geriatric Psychiatry, vol.6: 845-852, (1991).
- Furnish, S.A. Bradbury, N Riordan, J, *Psychological well-being for users of dementia services: Advice to purchasers and providers*. Briefing paper 2, British Psychological Society (BPS) Publications (1994).
- Hofman, A. Rocca, W.A. Bayne, C, *The prevalence of dementia in Europe: A collaborative study*. Int. J. Epidemiol. Vol 20: 736 – 745 (1991).
- Katzman R, *Clinical presentation of the course of Alzheimer's Disease: The atypical patient*. Interdiscipl. Top. Gerontol. 20, 12-18, (1985).
- Killeen J, *Advocacy and Dementia*, Alzheimer Scotland - Action on Dementia, (1994).
- Killeen J, *Health Care*, Alzheimer Scotland - Action on Dementia, (1994).
- Kitwood T, Buckland S, Petre T, *Brighter Futures*, Pub. Anchor Housing, (1995).
- Kitwood T & Benson S eds. *The New Culture of Dementia Care*, Hawker Pubs. London, (1995).
- Kitwood T, *Dementia reconsidered. The person comes first*, OU Press, (1997).
- Lawson W.B, Waldman, I.N, Weinberger D J, *Schizophrenic dementia: Clinical computed axial tomography correlates*, Nerv. Ment. Dis 176. 207-212, (1988).
- Matthews B. *Introducing the care programme approach to multidisciplinary team: the impact of clinical practice*. Psych. Bulletin 19, 143-145, (1995).
- Meltzer, D, Ely, M Brayne C, and Opit L, *The Cognitive Frail Elderly*, Dept. Community Medicine, Institute of Public Health, University of Cambridge (1995).

O'Connor, J and Ruddle, H, *Caring for the Elderly Part II. The Caring Process: A study of carers in the Home*, Dublin National Council for the Aged, (1988).

O Donovan, S. *Alzheimer's Disease and Dementia as an International issue*, Service Development Team, Cardiff Community Healthcare NHS Trust (1990).

OPCS, National Population Projections Number 17, Central Statistics Office, Social Trends, London: CSO, (1991).

*UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health*, (1991).

Schneidre J, Discussion Paper 932, Personal Social Service Research Unit, University of Kent, (1993).

# APPENDIX ONE

## Guidance for Case Study Writers on areas for analysis

### Block 1: National Level Systems and Policies

*Principal Investigator: Professor Morton Warner*

*Coordinating Analyst: Marcus Longley*

This Block concentrates on national policy, moving from a description of elements of the general policy context to an analysis of policies relating more specifically to Alzheimer's and related disorders. It is anticipated that approximately one third of the section devoted to Block One in each CSW's reports will address 1 to 3 below, and the remaining two-thirds section 4. The first three are intended to be descriptive - a straightforward, non-analytical presentation of the information - and the last more analytical.

#### 1. General Country Background (Description only)

- 1.1 Area, geography, industry, population distribution (include map)
- 1.2 Demography
- 1.3 Political structures and decision-making

*Note University of Glamorgan will provide a common core of internationally-available data. This will be sent to each CSW for validation, for the addition of specified data not available internationally (e.g. ethnic composition, religious persuasion, local languages, local distribution of economic and population data), and for the addition of other data deemed by the CSW to be particularly relevant in the circumstances of each country.*

#### 2. Health and Social Care Policies - etc. (Description only)

- 2.1 Inherent policy models e.g. self help or universal, categorical or population-wide etc.
- 2.2 Process for policy formulation - the key players and decision-makers
- 2.3 Fit between health and social care and social security policies
- 2.4 Level of conformity with WHO HFA principles (*to be completed by Glamorgan*)

*Note Descriptions of the process for policy formulation should be simple and might helpfully include a diagrammatic representation.*

#### 3. Health and Social Care Delivery - etc. (Description only)

- 3.1 What are the main organisational structures and accountabilities?
- 3.2 What are the principal sources of funding, and what are the main mechanisms for their distribution?
- 3.3 Describe the main features of the training and education of key professional groups

*Note Each country study should address both formal and informal care, **all** of the relevant professional groups, and informal and untrained carers. CSWs should concentrate on the **main** features of the systems being described.*



#### **4. Specific Alzheimer's and Neuro-degenerative Diseases Policies (Analysis)**

- 4.1 What is the recent history of policy developments? *(CSWs should identify the starting date most appropriate to their country. The term 'Alzheimer's Disease' is derived from current usage; CSWs should note that data from earlier periods may be categorised differently in their countries)*
- 4.2 What is the legislative framework for health, social care and Alzheimer's and neuro-degenerative diseases?
- 4.3 What are the financial arrangements for continuing care (e.g. use of insurance schemes)?
- 4.4 To what extent are finances specifically targeted to this group? *(CSWs should indicate the extent to which finances are specifically allocated, and the volume of resources so allocated or consumed (in relation to total expenditure). If there is no policy of specific allocation to this group, CSWs should describe the nearest proxy - e.g. resource allocation to older people, etc.)*
- 4.5 What attempts are being made to address issues of equity?
- 4.6 How (if at all) are HFA policies being applied to Alzheimer's and neuro-degenerative diseases? What are the aims and objectives of these policies?
- 4.7 Have targets been set to improve health and social gain for elderly people with neuro-degenerative conditions? For their carers?
- 4.8 What interrelationships exist with other relevant aspects of social policy? (e.g. welfare benefits, housing, means testing, social support services for carers).
- 4.9 How do national Alzheimer's and carers' organisations inform national policy?
- 4.10 How are policies and legislation affecting patients and their carers likely to change in the next 5 years?

### **Block 2: Methods and measures tests used in the detection and diagnosis of neuro-degenerative conditions in elderly people**

***Principal Investigator: Professor Brian Lawlor***

***Co-ordinating Analyst: Dr Margeret Kelleher***

The purpose of this block is to examine methods and measures used in the detection and diagnosis of Alzheimer's disease and neuro degenerative conditions in elderly people. The aim is to investigate the ways clinical and other decisions are made by the different professional bodies involved in the care of those suffering from Alzheimer's and other neuro degenerative diseases, and their carers and how this determines access to care and financial support

It would be helpful at the outset to describe the diagnostic classification system used in each country, together with any epidemiological information that might help address some of the questions and issues outlined below. It is also important to identify any written source material from national bodies representing the different professional bodies on the diagnosis and detection of dementia. This might exist as part of guidelines drawn up by that organisation and be available in professional libraries, or a contact at the headquarters of that professional body might identify appropriate sources. Another useful contact could be the

medical director of the national Alzheimer Society/Association. Professional bodies or organisations that might be contacted include:

- General Practitioners
- Psychiatrists (general, geriatric and mental handicap)
- Geriatricians
- Nursing organisations
- Alzheimer Society
- Community (visiting) Nurses
- Physicians
- Neurologists
- Voluntary Agencies
- Social Workers
- Psychologists

The following topics should be answered either from source material or by direct questioning - by phone or face-to-face interview - of a 'knowledgeable' informant, most likely a representative of the particular professional body or agency. It is important that the informant provides information that is representative of the national organisation or body and does not simply reflect his or her 'personal' viewpoint.

1. Do members of the organisation or professional body evaluate or assess elderly people (over 65) with dementia? Do they see people with presenile (onset before age 65) dementia?
2. If so, how do they make the diagnosis of dementia? Is it on the basis of symptoms only or do they also use a cognitive assessment instrument (e.g. Mini-Mental State Examination, Abbreviated Mental Test Score) or functional assessment (e.g. Activities of Daily Living, CAPE). Do they generally order any tests? Are there any written guidelines or procedures to help them in this task?
3. Are they aware of the subtle symptoms (memory loss interfering with function, losing one's way, progressive word finding difficulty) that may be indicative of early dementia? If in primary care, what types of problems or symptoms (if any) lead to referral on to specialists?
4. Do they try to differentiate between the different subtypes of dementia (e.g. vascular dementia and Alzheimer's disease)?
5. If a diagnosis of dementia is made, do they disclose it to the family? Do they disclose it to the patient? Are there guidelines?
6. If a diagnosis of dementia is made, what treatments are offered? (e.g. information, support, medications, advice regarding management)
7. What are the sociodemographic and economic characteristics of the people seen by members of your group?
8. Are they aware of recent advances (drugs, genetics, susceptibility factors) of Alzheimer's Disease?

## **Block 3: Perceptions and expectations of services, and current and future service provision**

*Principal Investigator: Professor Sally Furnish*

*Co-ordinating Analyst: Ms Christine Sime*

Block 3 investigates the implementation of national policies in the pattern and quality of current services and future service plans. The following main elements of services form the framework of analysis:

- Needs and Wants
- Personnel and Facilities
- Education and Training
- Programmes of Treatments and Care
- Research and Development

The documentary evidence on national policy collected for Block 1 will also be relevant for this Block. Additional sources of data for Block 3 are:

- Professional bodies
- Carers' organisations
- Voluntary agencies
- Regional/local service commissioners
- Regional/local service providers
- Formal regulatory bodies
- Advisory organisations on service provision
- Formal organisations involved in monitoring and evaluating services

### **1. Needs, Perceptions and Expectations**

- 1.1 Are Alzheimer's-related needs of a population considered in the country, and if so by whom?
- 1.2 How is demand for services predicted?
- 1.3 Are the needs of carers incorporated?
- 1.4 How is Alzheimer's Disease perceived by the public?
- 1.5 Does government policy imply an expectation that families will care?

### **2. Current Service Provision (personnel; facilities; education and training; programmes of treatment and care). This should include any services from assessment and information-giving to home care, day care, respite care, nursing and residential care.**

- 2.1 How are clinical and/or social services allocated? (e.g. eligibility criteria; means testing)
- 2.2 To what extent is the non-statutory sector involved in service provision? (*Non-statutory: voluntary and independent, profit-making organisations*)
- 2.3 What support is available to family care-givers?
- 2.4 Who makes up the main workforce? (e.g. gender, pay and conditions) - paid and unpaid workers.

- 2.5 Are there any qualifications or training for paid carers? (*Please define 'carer' when describing the workforce and describe any registration for carers.*)
- 2.6 Professional involvement in service provision - doctors, nurses, OTs, psychologists, remedial therapists, physiotherapists, speech therapists, etc.
- 2.7 What proportion of service costs are staff-related?
- 2.8 What is the balance of specialist and non-specialist facilities? (*'Specialist': specific provision for people with Alzheimer and related disorders is included/recognised*)
- 2.9 Type and availability of programmes of treatment and care.

### **3. Research and Future Service Developments**

- 3.1 What are the discrepancies between national and local policies?
- 3.2 Can service users and carers influence future service developments?
- 3.3 How are Alzheimer's related service funding priorities established?
- 3.4 How are future service plans influenced by Alzheimer's-related research?
- 3.5 What happens to people with Alzheimer's and related disorders not in contact with specialist services?

## **APPENDIX TWO**

### **Case Study Writers – Organisational Affiliations**

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