

**THE BOUNDARIES BETWEEN HEALTH  
AND SOCIAL CARE FOR OLDER PEOPLE  
IN DEVELOPED COUNTRIES**

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# **THE BOUNDARIES BETWEEN HEALTH AND SOCIAL CARE FOR OLDER PEOPLE IN DEVELOPED COUNTRIES**

*"We're all tackling the same problems of economic and social change... of family disintegration, of community breakdown and of social exclusion... and many of the solutions that will be adopted will be similar.... What I think is sensible is to throw it open to ideas and say let's talk about it and learn from one another."* (Rt. Hon. Tony Blair MP, Guardian Interview, 15 May 1998)

## **1. EXECUTIVE SUMMARY**

### **What is the report about?**

This report looks at how other countries provide care for frail older people and those with mental health problems. The report is concerned with the boundary problems that arise in providing care across various agencies. **It examines how the UK can learn from models of excellence in other countries.**

### **Why was the report commissioned?**

Three main reasons. First, **services for older people are not working as well as they should.** Second, **the numbers of older people in the UK are increasing, while the number of informal carers is unlikely to rise and may in fact fall.** Hence, **the pressure on care services is likely to rise.** Third, **the cost of chronic care is likely to increase in real terms,** fuelled by increasing labour costs, more expensive medicines/technology and rising health expectations.

Nevertheless, **it would be wrong to believe that there is a crisis in long-term care (LTC)** for three main reasons:

- the largest percentage increase in the numbers of older people (people over 65 years of age) in the UK has *already* taken place;
- eight out of ten older people live at home and need little formal assistance or already get satisfactory care in hospitals, the community or their own home;
- if UK growth continues on trend (around 2.5% a year), the costs of UK long-term care are only likely to rise by around 0.1% to 0.3% of GDP by 2030.

However, **there is little room for complacency.** The over 65s account for 40% of NHS spending and over £11 billion is spent on LTC alone - equivalent to around 20% of total UK health spending. Despite this high, and rising, level of spending, there is a feeling that significant structural problems remain. **Much more needs to be done to provide seamless care and to devise financing systems which encourage and reward innovation and good care practices.**

## **What are the main findings?**

The report describes the findings of a **nine month Study Fellowship** examining long-term care in the United States of America, New Zealand, Australia, Singapore, the Netherlands, Germany and Sweden.

The **key issues covered** include:

- the trend towards **the provision of 'person-centred' care**;
- resolving **the challenges around funding**, means-testing and inheritance;
- **how to improve quality** in the health service, social care and housing.

The **main political and policy dangers** in this area lie in:

- the *potentially high public expenditure costs* from improving access to care as people substitute formal for informal care;
- *targeting issues*, ie the need to balance greater expenditure on the genuinely needy with a need to improve existing services for the bulk of the population;
- the growing *difficulty of recruiting and retaining staff* in the caring professions.

The **report's findings** can be summarised under three broad headings:

- (1) **The 'modernising government' agenda.** The report looks at ideas of how to improve inter-agency working in order to improve and modernise the way government works;
- (2) **How to provide 'seamless' long-term care and mental health services.** It analyses models of cross-boundary working in other countries, examines ideas of how to achieve better integrated care and draws lessons to help improve UK services on the ground, thereby securing better value for money;
- (3) **Examples of good practice at the health and social care boundary.** The report documents specific examples of best practice from around the world.

### **1. Lessons For The UK's 'Modernising Government' Agenda**

This research shows that no country in the world has a blueprint for cross-boundary working which we can import unaltered, but there are some positive findings:

#### **The need for a strategy**

In countries such as New Zealand and Australia, where an effort has been made to draw up a **single strategy document setting out the goals and plans** to deliver high quality care, it has been easier to set a clear agenda and deliver improvements. Important elements in implementing a health and social care strategy are:

- *involve key agents and service users* in drawing up services;
- provide *dedicated funding* for service developments over a realistic time scale;
- draw up a *detailed implementation plan*, backed by proper monitoring.

**The watchwords for genuinely collaborative care are flexibility, dedication and creative services.** A broad strategy for integrated care should ensure that: care is person- and family-centred, with multidisciplinary needs assessment; accessible and adapted housing is available; there are transparent and flexible funding streams; care is provided by properly trained staff; people are assertively followed up and monitored with a focus on outcomes.

### **Improving the machinery of government**

**In many countries visited, communication between different central departments is believed to be worse than that between different layers of government.** Coordination often fails because middle managers in health and social services do not support coordination, since it violates their understanding of the culture of their services. Coordination between housing and health departments is notoriously poor. Remedies include:

- **reorganising ministerial responsibilities**, though UK and international attempts to brigade ministries together have not been very encouraging;
- **improving the coordination between ministries**, which requires a change in culture, leadership at director level and joint training programmes;
- **devolving power** to local government or agencies.

There are **few good international ideas about how to obtain more integrated central government policy.** They include:

- New Zealand is experimenting with '**clusters**' of ministers with related interests meeting under the chairmanship of a relatively neutral minister;
- the **number of ministries and officials involved in discussions should be kept as small as possible** (but others kept informed) and policy delivery needs to be issue-focused, rather than department-focused;
- **devolving power for health and social care downwards**, eg to local government as done in much of Northern Europe, means that communication failures between central government departments matter less. In Sweden,

municipalities are responsible for funding, and providing housing and social services, including nursing care in homes, and acute health care is the responsibility of the county council.

**Most countries visited combine responsibility for health and aged care in a single ministry - usually health.** Singapore is unusual in having a Community Development Ministry, which takes the government lead on aging issues, while the Health Ministry has responsibility for acute and mental health care.

Wherever power lies, whether in 'vertical' ministries (DH, DSS, etc) or in larger 'horizontal' ministries (eg DETR), boundaries will still exist. If the current structure is retained, **responsibility for aging might be usefully given to one minister**, since older people's interests are unlikely to be easily separated within a health ministry.

The concept of *person-centred care* points to the possibility of **making a single department responsible for advising and coordinating services for particular vulnerable groups**. Groups could be sponsored by different departments, eg in the UK, DETR might take responsibility for the homeless and DH for the disabled and older people (DSS have a claim, too, given the importance of benefit spending).

### **Integrating funding**

For people who need to access multiple services, the consensus is that **health and social services budgets need to be more integrated to deliver high quality care**. There are various ways to do this, including:

blended or pooled funds;

increasing the scope for home and community care agencies to work across departmental or organisational boundaries;

and instituting formal coordinated care pilots.

The UK has already passed legislation that addresses the first two options. The question is whether progress will be fast enough without further policy action.

Ultimately, without a **single funding source for chronic care**, it will be hard to deliver truly integrated care. Countries with systems of social insurance and the Scandinavian countries with comprehensive public health and social care systems get closest (but not very close) to unitary funding. However, even in these countries there are still significant operational boundaries between agencies at local level.

### **Cost sharing**

While most older people are asset-rich and income poor, **people of retirement age today have more disposable income** than their predecessors, although they are still unlikely to be able to pay for their care out of their income (costs faced by the chronically ill can easily exceed £25,000 a year). They may therefore have to sell their home. It is unrealistic to expect more than around 5% of people to take out

private long-term care insurance. However, **carefully designed co-payments** for some primary care as in Australasia and the USA may have a role to play.

The **challenge is therefore to find acceptable ways for people to meet the costs of LTC while not losing all their assets** (homes, pension funds, etc). Two ideas (detailed in the Issues chapter) which could be explored are:

- **creating a national LTC Fund** (which could be administered privately) to which all would contribute to pool risks between the healthy, frail and those who need long-term care, based on the principle of social insurance. It would be important to minimise its public expenditure consequences;
- **a mechanism to refinance the domestic housing market.** Given that most older people's wealth is tied up in their own homes, a financing vehicle could be set up which would re-mortgage domestic property. Typically, this would offer people a bond which paid interest in return for a share in the appreciated value of the home when the property was sold or changed ownership.

## 2. Delivering 'Seamless' Care

### Broad observations

Over the next 30 years, several factors mean that **a larger share of public spending is likely to go to those who need chronic, as opposed to acute, care:**

- continued ageing of the population, with *many more people living past 80*;
- older people, the disabled and people with mental health problems tend to have multiple, *interrelated and often complex health needs*;
- the *trend towards much shorter hospital lengths of stay* due to modern medical and surgical techniques.

**In order to deliver seamless care, 'person-centred care' is required.** With increasingly complex service delivery mechanisms, good outcomes are associated with making services revolve around people, *not* the other way round. **Holistic care is likely to be both more efficient and more effective**, consuming fewer total resources for a given output as well as yielding a better outcome for given inputs.

**Much evidence points to the fact that multidisciplinary teams are worthwhile.** In the UK, needs are mainly assessed by social workers. For people with high needs, multidisciplinary assessment (involving various professionals) helps to identify all the client's needs at the outset. It avoids the costly and time-consuming problems arising from undetected and unexpected complexity at a later stage in treatment. The challenge is that multidisciplinary teams are hard to run given different professional work cultures and the fact that specialist staff input is scarce.

This philosophical shift may mean that the era of **'vertical' care delivery systems may be waning.** Organisations which deliver care 'in one place' with vertical 'chains of command', eg hospitals and social services departments, have led to large health

and welfare gains, but these hierarchical organisations may have reached a natural limit in delivering better care (see section 2 of Issues chapter for further details).

**'Horizontal' forms of care delivery are better at providing integrated care.**

Examples of such models include: one-stop advice centres in Germany, 'Community Options' programs in the USA, coordinated care agencies, home and community care programmes in Australia and multidisciplinary mental health care in New Zealand.

**There are difficult hurdles to overcome in implementing 'horizontal' care.**

These include: the steep learning curve associated with fund pooling; the challenges of multidisciplinary team working; the difficulty of accurately targeting home health care on those who would otherwise be institutionalised and the shortage of unpaid carers and respite facilities.

**Seamless care clearly requires better information sharing.** Care planners and co-ordinators, social care agencies, GPs, hospital wards and pharmacies ought to be IT-linked and work to common protocols and administration forms.

Prevention and rehabilitation are also areas where existing practices can be inefficient. **Prevention advice should be clearly targeted** at changing or reinforcing particular behaviours. International best practice in geriatric care stresses the **importance of starting rehabilitation at the point of hospital admittance**, so as to prevent deterioration which requires costly bed stays to reverse.

### Organisational issues

**Major changes to the organisational boundary are unlikely in the near future.**

The Royal Commission's preferred approach of expanding services provided free at the point of use by the health service (eg personal care) would be costly and, without service reorganisation, would not directly improve quality - a key Ministerial goal. Nevertheless, it is clear that some action is needed to reduce boundary problems.

Less radical options include either **giving a lead to the newly created Primary Care Groups to co-ordinate community care** or **enhancing local government's role in organising and managing long term care**, for example by giving control and responsibility over community nursing and rehabilitation to social services authorities. Both options pose dilemmas and difficulties, explored in this report.

### Funding systems

The **major distinctive area of weakness for the UK is the financial borderline between health and social services.** The UK borderline between privately paid for and means-tested social services on the one hand and a free at the point of use NHS is unhelpful. Tinkering with means-testing tapers would almost certainly raise expenditure, but is still unlikely to completely resolve the underlying political issues about generational inheritance.

It is widely accepted that integration of funding would help to deliver more integrated care services on the ground. **Pooled budgets will help, but more uniformity in**

**charging and co-payments**, as well as **pushing take-up of direct payments**, **should also be explored** in return for better or guaranteed access to services.

The type of care that needs to be provided depends on the state of health of an older person. Blanket care coordination or integration is unwise and costly. Older people fall into three categories: the well, frail or disabled:

- best practice for the healthy uses a **comprehensive preventive approach**, combining public health education with private efforts of *The Center for Healthy Aging* (USA);
- The frail need **improved sheltered housing and co-ordinated care packages** of *Humanitas* (Netherlands) or *Mercy Family Centre* (Australia);
- The disabled require funds to be pooled from multiple systems to create a **fully integrated care programme** managed by a dedicated case manager of *Wisconsin Partnership Project* (USA) or *Co-ordinated Care Trials* (Australia).

Older people still spend too long in acute care, though lengths of stay are falling. 'Revolving door' admissions are also still too common. International evidence suggests that **people can be effectively and adequately cared for in homely settings**. For this to work well, there needs to be:

- **overall management by someone skilled in care for older people**. This could be, but need not necessarily be, a geriatrician;
- **comprehensive assessment systems**. For clients with multiple complex care needs, it is vital that a care manager oversees their care;
- **good links between the client, GP and other care professionals**. Family doctors play a particularly crucial role;
- **a full range of community support options**, including carefully targeted respite care for those who need more than family-based care.

**Careful thought needs to be given to current organisational and financial incentives to remove any bias towards institutional care**, eg charging rules which make residential care cheaper than domiciliary care. Experiments with providing case managed community care showed that it might postpone entry to institutional care for about two years.

In housing, the main gain, aside from better central government coordination in supporting local initiatives, is likely to come about by **ensuring that older people live in safe and suitable environments**. This is the long-term care equivalent of the environmental gains from home insulation. **Easier and cheaper access to advice about low-cost home adaptations** could also reduce the number of accidents and falls in the home and the associated care costs and trauma suffered by older people.

### 3. Lessons from International Experience

#### Where can the UK improve and share its own existing good practice?

In some areas, the UK is already at or around the leading edge and should do what it is already doing and disseminate good practice. Some examples are:

- **building capacity in the community to enable people to help themselves.** UK Health Action Zones are encouraging people from deprived communities to take more active roles in the community, although the benefit system still makes it hard to combine work and other interests;
- **encouraging PCGs/GPs to be more involved in coordinated care.** However, international experience suggests GPs should not directly coordinate care (as they would need special training to carry out this function), but instead be kept fully involved in their patients' care arrangements;
- **helping consumers to become more informed users of health care.** Capitated funding sets the right framework, but it is vital to help consumers become informed users of health and social care. The US Foundation for Accountability and the UK Audit Commission are doing much useful work in this area. The UK could also use its innovative 'NHS Direct' telephone advice service to provide pro-active ill-health prevention advice;
- **consolidating successful initiatives by incorporating one-off monies into mainstream funding.** An example is 'winter pressures' money, where it has been used constructively to address structural issues, eg through funding joint teams for care for the elderly. The benefit of this funding will be lost if it is not incorporated into recurring funding;
- **reducing wasteful structures and practices.** The UK has cut average hospital lengths of stay markedly in the last ten years, but more methodical triage and pre-admission procedures could reduce stays further. More action could also be taken to reduce the overmedication of some older people.

#### Where can the UK learn from other countries?

Besides improving the links between the hospital and the community, reducing inappropriate stays in hospital and providing better prevention and health education, the UK can clearly learn from other countries in three other areas:

- The UK can learn from US experiments with '**consumer-directed care**' and German experience with **LTC cash allowances**. The USA is piloting a form of consumer direction in which personal care services are provided by home care workers, who are selected, trained and supervised by the consumer, with individuals using cash payments to purchase the support they need. The evaluation to date has shown positive results. In Germany, the LTC insurance system has generated significant savings through a high take-up of cash allowances, despite these being set at a lower value than care-in-kind.



- **Reinventing geriatric practice.** This is an idea invented and exported by the UK, but geriatric practice now plays a more important role in other countries (eg Australia) than it does in the UK. The evidence is a little mixed, but geriatrician-led programmes, particularly outside hospitals, and working closely with GPs can provide more comprehensive and effective health care for older people with complex needs.
- A **wider choice of housing options is necessary** to help people make the transition between hospital, nursing home and their own home. US and continental assisted living and high-end shelter-with-care options need to be studied. Where controls have been placed on the building of new nursing homes, such as in the USA and Australia, it seems to have been effective in stimulating domiciliary and other more popular residential care options.

### **Where can the UK improve and share its own existing good practice?**

The key messages are:

- bolster moves to a **population and public health focus**, which provides a common framework for discussion;
- **engage everyone** in drawing up a strategy - especially users and carers;
- **flexible resources** will be needed in the future to continue innovation;
- **better information systems** are required;
- **partnerships** with primary care, substance misuse teams et al will be key;
- there is a clear need to **develop quality tools** - guidelines, outcomes and report cards.



# **THE BOUNDARIES BETWEEN HEALTH AND SOCIAL CARE FOR OLDER PEOPLE IN DEVELOPED COUNTRIES**

## **2. INTRODUCTION**

*"All too often when people have complex needs spanning both health and social care good quality services are sacrificed for sterile arguments about boundaries. When this happens people, often the most frail and vulnerable in our society - the frail elderly, the mentally ill - and those who care for them find themselves in a no man's land between health and social services. This is not what people want or need. It places the needs of the organisation above the needs of the people they are there to serve. It is poor organisation, poor practice, poor use of taxpayers' money - it is unacceptable."*

**(Extract from Foreword of *Partnership in Action*, UK Department of Health Discussion Document, September 1998)**

### **Aims and objectives of the report**

1. The health policy debate has tended to be dominated by issues raised by acute and emergency services: discussion of the relative priority between preventive, chronic and acute health care and the boundaries within and between these services has often been given low priority.
2. But the rapid increase in the numbers of those over 65 and 85 years of age, combined with the rapidly increasing prevalence of chronic disease and disability are stimulating much greater attention in developed countries on issues of disabilities and the need to provide appropriate and contiguous services for the elderly and disabled groups.
3. Comparative analyses of international long-term care systems have been carried out by the OECD (for example, *Caring for the Frail Elderly: Policies in Evolution*, 1996 and *Health Care Reform: The Will to Change*, 1996). This report does not attempt to replicate these comparative studies but instead focuses specifically on the way the boundaries between acute, post-acute medical care, long term or chronic care, housing and social care are managed in developed countries.
4. This report aims to:
  - document long-term care and mental health systems in use in other developed countries;
  - compare and contrast problems and practice elsewhere with the UK;
  - provide some lessons and pointers to how care boundaries for the elderly and users of mental health services might be better managed in the UK.

## **The methodology**

5. The report has emerged from a process of formulation, consultation and feedback involving six stages. First, a study proposal was formulated in consultation with the health policy team in HM Treasury and economic experts in the UK Department of Health.

6. Having clarified the precise area of study - the boundary between health care and social care for the elderly and users of mental health services - and drawn up a list of key issues (see Annex B attached) which needed to be addressed in the UK, the second stage involved 'road testing' these key issues with various people in the UK who have a clear stake in the UK system of long-term care and mental health.

7. The aim of this process was to ensure that I had a clear idea of current UK practices and problems before going to examine systems and practice overseas. I am very grateful to a number of individuals (see Annex A) for taking part at an initial stage in drawing up the questions and issues to be addressed in the report.

8. The third, international, stage of the work involved travel to the USA, New Zealand, Australia, Singapore, Sweden, the Netherlands and Germany to interview and discuss issues with leading academics, policy makers, lobbyists and care deliverers/practitioners in each country. Since there was not time to see everyone in the field in each country, a key individual or first point of contact was selected in each country, usually a key adviser in the Department of Health, who then suggested further contacts.

9. The most interesting of the interviews and the most pertinent observations, combined with relevant material and publications where this had been supplied to me, form the basis for the country chapters and thematic review sections of the report. The documentary material supplied by my contacts, which comprises a sizeable number of publications, articles and programme documentation collected during the research, is available for reference and consultation.

10. The next two stages of the Fellowship involved peer review of the emerging findings. In the fourth stage, the first draft of the country chapters was sent to several key contacts in each of the countries visited for their comments. These comments were incorporated into an improved second draft of the report. The fifth stage involved discussion of the findings from the non-European countries visited - the USA, New Zealand, Australia and Singapore - with the UK-based individuals who were consulted at the earlier second stage. I gave a series of presentations and seminars in spring and summer 1999, explaining the emerging themes and findings. The issues, questions and comments raised in this round of discussions were used to further review the material collected and informed the conduct of European visits.

11. In the sixth and final stage, a draft of the final report was circulated to the Treasury and Department of Health and two key contacts in each country visited, before being written up and finally circulated to the sponsoring Departments.

## Report structure

12. Besides an Executive Summary, which draws out the main findings and lessons, the Report is structured into three broad sections:

- (i) an **account of health and social care systems, problems and practices** in the seven key developed countries visited;
- (ii) an **account of innovative or useful care services and practices** in the countries visited, which have lessons for UK and other policy makers;
- (iii) a **cross-cutting/cross-country examination of the main policy issues** (strategic, service delivery and financing) affecting health and long-term care for the elderly and mentally ill.

Sections (i) and (ii) are incorporated in the country chapters, while section (iii) forms a free-standing ('Issues') chapter.

## **ANNEX A**

The individuals consulted at the outset of the project were:

### **UK Civil Service**

Robert Culpin, Director of Spending in HM Treasury, and Gill Noble, Deputy Director with responsibility for health spending, HM Treasury;

Andrew Hudson, Sue Catchpole and Mike Evershed in HM Treasury's health team;

John Aldridge, Gavin Anderson and Gill Otley in the Scottish Office Health Department;

Alan Davey and Patrick Hennessy, Secretariat, Royal Commission on Long Term Care, Department of Health;

### **Academics and commentators**

Professors John Hills and Howard Glennester, LSE and CASE;

Professors Bleddyn Davies and Martin Knapp, PSSRU and LSE;

Professor Gerald Wistow and Brian Hardy, Nuffield Institute, Leeds;

Janice Robinson, King's Fund;

David Browning, Audit Commission;

### **Practitioners**

Anne Windiate, Director, Riverside Mental Health Trust;

Cath Cunningham, Local Government Association;

Chris Bull, Southwark Social Services;

Philip King and Naomi Landau, Soho Community Mental Health Team;

Dr Geraldine Strathdee, Oxleas Mental Health Trust.

## **ANNEX B**

### **ISSUES/QUESTIONS**

This note sets out the main questions to be explored in research undertaken as part of a 1998/99 UK Government Study Fellowship. The research will look at and report experience of dealing with the boundary between health and social care in the USA, New Zealand, Australia, the Far East and Europe. The issues addressed by the Fellowship have been chosen because of their importance for government policy in the UK. The issues and questions have been deliberately cast in fairly broad terms so as to stimulate a wide range of ideas and unearth innovations and good practice.

Interest in the issues listed below will vary by country and between states/provinces within countries. In each country or state, discussions will concentrate on those issues of most local relevance. It is therefore not the intention to address all the issues in all countries or with every interlocuter.

There are four main areas of interest:

1. The strategic framework for delivering care
2. The roles and responsibilities of the relevant agencies
3. The delivery of services and accountability mechanisms
4. Financial issues, incentives and rewards

#### **The strategic framework for delivering care**

What is the strategic framework for delivering health and social care to the elderly and mental health populations?

Is an overall strategy or vision shared by the key agencies? If so, how is it manifested and expressed?

Is there consensus between relevant agencies about how care should be delivered?

#### **The roles and responsibilities of the relevant agencies**

Have the roles and responsibilities of the relevant agencies/professionals been clearly defined? Are these roles accepted and understood? Where are the boundaries?

Is 'seamless' care an objective? What boundary or programme cross-working issues remain to be resolved? How might they be overcome?

Are there lessons for general government from the experience of dealing with clients with long term-care or mental health needs?

## **The delivery of services and accountability mechanisms**

How are elderly/mental health services provided? What is the balance between country/federal, state/provincial, profit not-for-profit and family provision?

Does a unified organisational structure exist? Is there a unified care budget ? Are services formally planned or commissioned? How do current organisational structures promote or impede collaboration?

In what ways are agencies and professionals held to account? Is value for money an explicit objective? How is monitoring and performance management used to review strategy and care responsibilities?

## **Financial issues, incentives and rewards**

Are services charged for? If so, how and for which client groups? How is the line drawn between charged and non-charged services? Is public sector-funded coverage expanding or contracting? Is there consensus on charging?

What financial incentives and rewards are perceived to exist? Do these promote or damage collaboration in delivering care? If so, how?

Does cost-shifting take place? If so, to whom? How are the resulting problems and conflicts managed?

**Mark Minford  
HM Treasury  
United Kingdom  
August 1998**



# **A STUDY OF THE BOUNDARIES BETWEEN HEALTH AND SOCIAL CARE FOR OLDER PEOPLE IN DEVELOPED COUNTRIES**

## **3. COUNTRY CHAPTERS**

### **A. UNITED STATES**

#### **A1.1 Summary and Overview**

##### The big picture

The main features of the US health and long-term care systems are:

the US health care system has **relative deficiencies in cost and coverage**. US health spending at 13.5% of GDP is around double the UK's, while over 40 million Americans are not continuously insured to receive medical care;

the health care **system is more socialised** than many Americans realise. Federal and state governments purchase health care for over a quarter of all Americans through Medicare and Medicaid, and over a third of the cost of health services delivered in the US are paid for through taxation;

after the failure of the Clinton health reform plan, there is still **a good deal of dissatisfaction with the system of acute and long-term care**. There are few signs of long-term care rising up the political agenda;

**managed care is on the ascendant** within the health system, motivated by concerns about cost pressures. More older people are enrolling in managed care plans, but with the exception of a small fraction of very dependent elders enrolled in Social Health Maintenance Organisations and integrated care projects, this model struggles to bridge the health/long-term care divide and may not end up saving much money (much depends on the rate paid);

there is **interest in finding ways to integrate acute and long-term care**. Quite a few states and several demonstration projects, eg PACE, Community Options/Partnership models and SHMOs are testing integration, though the benefits of Medicare and Medicaid integration still remain to be proven;

The biggest strength of the US system is also its most obvious weakness. US consumers have high expectations, and the **system treats people as individuals, which can ensure excellent person-centred care** and avoids depersonalisation common in more socialised systems. This attitude has now been enshrined in law through the 1990 Americans with Disabilities Act (ADA). But this philosophy of individualised provision and plurality means that **care is fragmented through a multiplicity of providers**, with resulting high transactions costs, and quite a few people - particularly those with mental illness - can fall through the care 'net'.

Nevertheless, surprisingly, **UK and US systems of long-term care are more similar than they appear at first sight**, especially after the recent market-driven

reforms to the NHS. The obvious difference in funding mechanisms - tax funding versus insurance-based funding - can obscure the fact that the split in the UK between health and social care is mirrored in the US Medicare/Medicaid split. The US health care system ensures that the main medical needs of older Americans (defined as those over 65) are covered under Medicare, as the NHS does in the UK.

Similarly, the **US Medicaid health care programme provides a residual welfare net**, funding care in nursing homes, other institutional settings and at home. Comparable social services are provided in the UK by local authorities. In both the UK and US, charging and spend-down of assets are a feature of access to publicly funded care, and there is a significant minority of people who pay for their care in nursing and residential homes out of their own pocket.

In terms of general medical care, a key difference compared to the UK is that there is **significantly poorer medical coverage in the USA**, although where it is provided to the insured, the *quality* of acute medical intervention is generally high. But the difference in the UK may be less marked for the elderly, given the existence of waiting lists and difficulty of getting routine treatments (kidney dialysis, cataract operations and hip replacements).

The US **system is more generous in the treatment of assets for the poorest** - especially under partnership insurance schemes. Although the UK allows people higher levels of liquid assets, the house is included for assessment purposes. This is not the case in the US. Historically, Medicare has not provided much funding for long-term care and, although policy in both countries is nominally oriented towards care in home and community based settings, the feeling still prevails in both systems that **care is still overly biased towards medical and institutional care**.

Many commentators are agreed that there is a need to establish a financing structure that allows providers to collaborate and deliver more 'seamless' care for the elderly. Although long-term care was not a big part of the Clinton health reform, the failure of the plan to get Congressional approval - due partly to the complexity and poor marketing of the proposals - has meant that there has not been much discussion in the late 1990s about the health/social services borderline in the USA. But thanks to quality of care scandals, the impact of the Balanced Budget Act and President Clinton's 1999 proposals, **long-term care is slowly rising up the political agenda**.

But the difficulties of dealing with the financial and legal framework mean that **there are some innovative and path-breaking attempts to work across funding and organisational boundaries**, including the Social HMO model, PACE experiments and attempts by states, eg Minnesota, to provide health and support services in a coordinated way.

The main features of the best projects were: the provision of person-centred care with a focus on outcomes for individuals and keeping them healthy and active in their own homes for as long as possible (goals vary by target group, eg the frail and very dependent); clear interdisciplinary working and the pooling of funding streams by service providers.

## Strengths and weaknesses

The rest of the world can learn from the positive aspects of the US system, which include a strong consumer focus and highly innovative practices:

a deep-seated **desire for, and emphasis on, consumer-directed care** and choice. At its best (and where people have insurance), this leads to an impressively high level of care;

a **wide range of innovative practices** in various states, companies and not-for-profit organisations which have useful lessons (see Best Practice section);

a **strong and pluralistic research base**. Well-endowed funds, such as the Robert Wood Johnson Foundation among others, provide large amounts of funding (by European standards) for service innovations and pilot schemes.

The weaknesses of the current long-term care system are:

a **lack of transparency and poor information**. One part of the medical service is often unaware of what another part is doing. A lack of provider coordination hampers effective service delivery and raises costs;

**uncoordinated and variable service delivery**. Multiple funding sources (Medicare, Medicaid, State grants, insurance, charitable and private funds) mean that service delivery and funding for a particular type of care, eg home-based care, is patchy and fragmented. Since state systems vary, there is also little geographic homogeneity and service standards vary hugely;

**strong cost pressures**. The fee-for-service system has a built-in tendency to over-medicalise and over-prescribe. Long-term care costs for the elderly are growing fast and account for a significant share (around 12%) of total health spending;

**high transactions costs**. Administrative costs are very high - up to 15% of total health care spending for some providers;

Some older people (and younger people with prolonged or intensive acute care needs) face **catastrophic out-of-pocket expenses**. Policy ensures that applicants for publicly-funded care must 'spend down' to poverty level before receiving help.

## The future?

Underlying **US cost and quality problems have not gone away**. Health care costs are high and growing: real spending growth in Medicare and Medicaid is around double real GDP growth (figures from mid-90s). While health care is income elastic and so you would expect to see real spending increases there is little political will for the public purse to shoulder these costs as nursing home and home health care already accounts for one-seventh of all state and local health spending.

Private health expenditure is also already high, and there are calls for higher spending, eg on drugs. This fuels a state of mind bordering on paranoia in Congress towards any call for reform and/or increased public outlays on the elderly.

**Demographic trends** are also worrying for policymakers. Alongside the real increase in the cost of the existing programmes, the number of potential beneficiaries are also growing rapidly as the baby boom generation ages. The number of American elderly in nursing homes is projected to increase from 2.2 million in 1993 to 3.6 million in 2018, and users of home care are projected to increase from 5.2 to 7.4 million.

## A1.2 The Strategic Framework

While the Department of Health and Human Services (DHHS) is supportive of the move to more community-based care and alternatives to institutional care in light of the recognition that nursing homes are not popular, it is fair to say that there is no identifiable single national strategy on health and long-term care. The care framework is characterised by plurality and experimentation.

The US health and social care strategy and structure is unusually complex - arguably over-complex - by international standards. It reflects a history of legislative developments as well as shifting Congressional and state attitudes and concerns. According to Urban Institute researcher Josh Wiener, the current US long-term care structure is "haphazard" and "does not reflect a deliberate policy choice about the appropriate role of government".

There is a plethora of individual health and social programmes in the long-term care field alone, but these do not add up to a coherent whole. The picture painted by those intimately acquainted with the administration of the health care system is one of sclerosis - an unintentional medicalisation of care and obsessive Congressional tinkering. Since 1981, the Budget Resolution has acted as a powerful agency enforcing the status quo, as any changes have to be justified against the current spending base line, while legitimising micro-management of the system through statutory changes.

Medicare was designed in 1965 to cover all elderly people, although life expectancy for farmers and workers was shorter than it is now, and was intended to replace private insurance which was no longer generally affordable. Two factors have acted to increase pressure on public funds:

the attractiveness of Medicare as a 'cash cow' for private providers. The fact that Medicare is a medical programme has acted to justify payments for 'skilled' interventions and therapies performed and advocated by medical pressure groups;

a slight but discernable trend to substitute informal for formal care. National surveys show that the number of disabled elders relying on informal care alone has fallen slightly from 75% to 66% between 1982 and 1994.

Medicaid always covered a broader set of services than Medicare, but is still seen as an essentially medical programme. Opinions differ about how tightly controlled Medicaid has been by federal statutory regulation. Although Federal officials felt they could never control the programme, as states had enormous discretion, funds have only been made available on the basis of a detailed set of conditions. Over the years, the policy is gradually moving from a statute basis to greater freedom for states. According to HCFA, policy is increasingly being made by exception to existing statutes, for example through the home and community-based care waiver programme. The waiver programme gave states a licence to move away from medically oriented care packages and provide new forms of long-term care, eg non-medical case management, respite care and response alarms. Consequently, spending on these programs has since risen sharply.

Another important point in this context is that a substantial part (perhaps around two-thirds) of long-term care expenditures, especially Medicaid home and community-based service waivers, are spent on behalf of the learning disabled. Most of the growth in waivers and long-term care spending is generally due to the learning disabled, not the elderly. In the light of this history, a big strategic concern is how to control ballooning publicly funded long-term care costs (see also text on 'Cost Containment' (A1.6 in Section 2). The Federal Government and states are exploring three main strategies to control spending:

increasing private sector contributions to long-term care costs;

reforming the system;

conventional cost cutting and supply management strategies.

### **1.2.1 Increasing private sector contributions**

There has been a concerted attempt over a number of years to encourage individual contributions to health costs in a number of ways. States are trying to bring outside resources into the long-term care by: encouraging private medical insurance and 'Partnership' insurance schemes; recouping the costs of providing long-term care through tightening up the means-testing framework and transferring costs to Medicare.

In order to encourage the purchase of **private long-term care insurance**, the Federal Government has provided some tax incentives. For example, the 1996 Health Insurance Portability and Accountability (HIPA) Act enabled the portability of health insurance, encouraged corporations to offer LTC insurance and allowed premiums and provisions and contributions to Individual Retirement Accounts to be tax deductible.

This flexibility has been used by some states to encourage LTC insurance. A bill is also currently under discussion to create an LTC insurance product for federal employees, but is unlikely to be passed quickly. The size of potential enrollees allows the Government to get round one of the potential problems of insurance - namely the need for an adequate risk pool over which to spread likely claims.

Various states have also tried to encourage LTC insurance with **partnership schemes**. Under these partnerships, states apply more generous Medicaid asset standards to individuals who purchase an approved long-term care insurance policy. These policy encouragements have foundered on three problems: myopia and unwillingness to purchase policies when they are affordable - ie before retirement; disinterest in easier access to Medicaid; the typically high cost to income ratios of the policies.

Private care insurance is only ever likely to be a minority pursuit. Most studies in the USA have found that only 10% to 20% of the elderly can afford private medical insurance and currently, despite an intensive marketing campaign, only 5% of the people over 65 have any type of long-term care insurance (see Issues section in part

2 of this chapter for a further discussion of LTC insurance).

As in the UK and elsewhere, state and federal legislatures have sought to recoup costs through **closing loopholes in the means-testing system**. Examples include reducing the potential for divestiture or 'estate planning' (appearing poor on paper but preserving private wealth), stricter income testing and greater asset recovery after death. The 1997 Balanced Budget Act was the most recent attempt to outlaw estate planning.

But, while necessary, this strategy for cost control does not promise a rich harvest. The limited evidence which exists - eg a 1993 GAO study - suggests that evasion is more limited than commonly thought and, in any case, most older people with disabilities, and especially the very old who account for a large majority of nursing home patients, have pretty low income and asset levels. Asset recovery in 1995 was \$125 million, less than half of one per cent of Medicaid nursing home expenditures for the elderly. Even the most successful estate recovery programs only averaged 1% of Medicaid nursing home expenditures.

### **1.2.2 System reform**

The second general strategy for saving money has been to try to provide long-term care more flexibly. This is probably the most fertile avenue in the long run for controlling costs. Two main approaches have been tried:

extending managed care to include long-term (as well as acute) care services;

expanding home care and community options models of long-term care.

There is increasing interest among policymakers in finding ways to integrate the acute and long-term care sectors, mainly through **expanding the role of managed care and capitated payments to include long-term care services**. Various demonstration projects are under way, encouraged by the National Chronic Care Consortium, to test different approaches to integration. These include: On Lok and the Program of All-inclusive Care for the Elderly (PACE), Social Health Maintenance Organisations and the Arizona Long Term Care System.

Several states, including Colorado, Maine, Massachusetts, Minnesota, Texas and Wisconsin (Minnesota and Wisconsin were visited on the Fellowship) are undertaking demonstration efforts to coordinate care through state-run managed care models (of private provision) using Medicare and Medicaid waivers. The Health Care Financing Administration (HCFA) has, however, been unwilling for the states to combine Medicare and Medicaid monies into a single state-administered capitation payment to managed care organisations and has insisted that enrollment be voluntary. These models are explored in some detail in the Service Delivery section in Part 1 below.

Many other states, including New York, Oregon and California (Oregon and California were visited) believe that **expanding home and community-based services** is a cost-saving strategy. Besides promoting assisted living models and undertaking 'Cash and Counselling' experiments, most states have obtained

Medicaid home- and community-based service waivers in an attempt to expand non-institutional services. Regulatory changes made by the Clinton administration have made obtaining waivers easier, though still far from trivial. After a slow start, home- and community-based waiver expenditures have risen massively from under \$0.5 billion in 1987 to \$4.6 billion in 1995 and \$8.1 billion in 1997/98 (see Annex 1 for more detailed information on Medicaid spending).

HCFA has enforced the conditions on the waivers laid down by statute:

states must target people at high risk of institutionalisation;

on average, the cost of services provided must not exceed the cost without the waiver;

there is usually a pre-agreed ceiling set on the number of people to be served, to limit the potential financial liability.

Although states have hoped to save money, there is a danger, confirmed by some research, that expanding home care is more likely to increase than decrease total long-term care costs. This is largely due to the much-mentioned and feared 'woodwork' effect, whereby people who would have foregone paid services if they were only offered nursing home care would come 'out of the woodwork' and accept home care services if these were made available.

But recent research, looking at the operation of programmes in Washington, Oregon and Colorado, is more encouraging and suggests that, with careful design, home- and community-based care can be a cost-effective alternative to institutional care. The tricky part is accurately targeting home health services on that part of the population that would otherwise have gone into long-term care. It will be interesting to see if the optimistic research findings hold true in more densely populated states like New York or California.

### **1.2.3 Cost reduction and supply management strategies**

Existing federal law gives states considerable flexibility to use conventional cost cutting-mechanisms, such as cuts in eligibility, changes to the extent and coverage of services and reductions in provider reimbursement rates. However, even with the repeal of the Boren Amendment to the 1980 Omnibus Reconciliation Act which set minimum standards for Medicaid nursing home reimbursement (and which arguably forced states to spend too much on nursing home care), the ability of local legislators to defy the powerful nursing home lobby and reduce reimbursement rates is probably limited.

There is also the question of whether, with Medicaid nursing home payment rates already fairly low in most states (averaging \$85 a day in 1995 prices), especially compared to Medicare and private pay rates, reducing reimbursement rates would be desirable as it might worsen standards and create further access problems for Medicaid beneficiaries.

The most effective short-term solution to reducing costs - also adopted in Australia - appears to be prohibiting the construction of new nursing home beds (on the not



unreasonable assumption that they would be likely to be mainly occupied by Medicaid-funded residents).

By 1995, 17 states, including Wisconsin and Oregon, already had a moratorium on new nursing home construction. There is a danger, though, that this solution might only offer short-term rather than long-term savings. Whether this is so depends on whether there is diversion from nursing home into other publicly funded provision such as home care and whether the resulting 'shortage' of nursing home places does not cause a silting up of patients in hospital and pressures for dangerously early discharge.

### **A1.3 Roles and Responsibilities of Different Agencies**

The elderly who need long-term care services currently encounter a fragmented financing and delivery system, although as in Australia, the division of responsibilities between the Federal Government and states is pretty clear. Annex 1 provides a brief description of the US health care system.

The Federal Government finances acute care largely through Medicare. Medicaid and state governments pick up most of the cost long-term care financing, including the bulk of nursing home care, although Medicare is funding an increasing amount of home health care. Essentially, Medicare functions as medical insurance for the elderly, while Medicaid provides a welfare 'net' for middle income Americans who have impoverished themselves through 'spend down' as well as the poor.

States now have a good deal of discretion as to how the Medicaid programme is run, eg whether a personal care benefit is offered and what limits there are on spending. Medicaid coverage is increasingly broad - for example, it offers a home health benefit, which provides nursing help, therapists' services and it can even offer personal care assistance.

Facilitated by relaxations in Medicare and Medicaid coverage rules, there has been an increased use of formal care in the home, funded both by public payments and out-of-pocket payments. Successive national long-term care surveys have shown that the numbers relying on informal care provision have fallen. A typical disabled elderly person needing assistance with 3 activities of daily living (ADLs) might use 75 hours of care a week, of which 60 hours would be provided by the family (usually the spouse in a married couple) and 15 hours by paid care givers.

### **A1.4 Financing Arrangements and Accountability Mechanisms**

Long-term care services for older adults represent a substantial share of total health care spending. The average cost of nursing home care amounts to \$40,000 per annum, with the cost rising to \$75,000 and even \$90,000 in some urban areas. Not surprisingly, nursing home and home health care therefore represent a very significant part of total health care spending: around 15% of total state and local health spending and around 12% of private health care expenditure (figures from mid 1990s). See Annex 1 for summary details of US LTC spending.

### **1.4.1 Funding mechanisms**

Neither Medicare nor private insurance covers long-term care to any significant extent, and less than 5% of the elderly have private long-term care insurance. The frail elderly must therefore rely on their own resources or, when these have been depleted, turn to Medicaid to pay for long-term care. Medicaid is the dominant source of public financing of long term care for the elderly. This type of expenditure is expected to more than double in real terms in the next 20 to 30 years, due to the population aging and to (care) price increases above general inflation.

US nursing home care is just as expensive as in the UK (if not more so, relative to average incomes), with an average of around \$40,000 \$45,000 per annum. Medicaid therefore provides an important safety net for middle-class Americans, as well as the poor. In 1997, 68% of nursing-home residents were dependent on Medicaid to finance their care. Data I have seen suggests that about a third of ex-nursing home residents pay privately when admitted and eventually spend down to Medicaid eligibility levels.

To qualify for Medicaid payments, single people must have less than \$2,000 in assets, besides their home and must spend all of their income on their care except a small personal needs allowance of around \$30 a month with Medicaid providing a top-up payment. As in the UK, married couples can keep significantly more of their income and assets (which is a pretty strong incentive to stay married in later life).

The breakdown of the sources of long-term care spending is roughly as follows:

<u>Funding source</u>	<u>Percentage</u>	
Medicaid	35	
Personal/family spending	40	
Medicare		20
Other Federal/state spending	5	
Private insurance	1	
Total	100	

These figures date from 1993, but the pattern of funding will not have changed a great deal. Medicaid and out-of-pocket expenses are the primary sources of financing of long- term care for the elderly. The figures above understate the importance of Medicaid because contributions of income by Medicaid beneficiaries towards the cost of care are counted as out-of-pocket rather than as a part of the Medicaid payment. The importance of Medicaid funding gives public authorities a good deal of potential leverage over institutionalised providers and conversely means the legislatures are the recipients of powerful and sustained lobbying activity.

### **1.4.2 Accountability mechanisms**

The structure of health insurance and health-care delivery is changing rapidly in the USA. Medical innovation and computer technology may lead to better accountability

USA. Medical innovation and computer technology may lead to better accountability for performance and outcomes. The restructuring - towards managed care models with consequential effects on providers and physicians - could also enhance patient care and outcomes.

But, clearly, there are risks in this process. While the policy focus remains on under-coverage of a large section of the American population, the reality is a cash-crunch on the part of public and private organisations, which is hampering efforts to focus on quality and cost-effectiveness of care. The US system is characterised by three features:

excessively (even obsessively) detailed rules and regulations concerning funding, the appropriate use of funds, service standards and levels - eg the Californian rules regarding nursing homes resemble a large dictionary;

a strong focus on the quality of care in institutions - motivated by individual concerns and scandals in the quality of care in nursing homes. However, there are few consistent tools used to measure and manage quality;

an unwillingness by some providers to bear responsibility for care in the light of an increasingly litigious environment.

This means that, in practice, responsibility for care outcomes is passed from one provider to another, which leads to further confusion among both providers and consumers. No-one can satisfactorily track how much services really cost because payments are fragmented between programmes and payers, and price is therefore generally used as a substitute. There is a real feeling among governors and senators - sometimes fuelled by Congressional Budget Office analysis - that spending is out of control, although currently this is not the case for either Medicare home-health spending or Medicaid spending.

There are big issues about who makes the important decisions, the choices that are offered and the information on which decisions are made. The problem is that people and organisations know very little about the relative performance of different health plans and their respective abilities to meet people's needs for end-of-life care. Choice is almost sacrosanct to Americans, but although within Medicare there are 39 million people who are in an environment of free choice, very few of them are in practice actively exercising choice.

The general approach that seems to be most popular is not audit-driven, but consumer-led. A broad consensus is emerging in the USA about the importance of devising measures of health-care quality and empowering and informing consumers through their use. Quality measurement and consumer reporting are mentioned in almost every health-care proposal currently under consideration in Washington. Gradually, purchasing coalitions, individual corporations, government agencies, accrediting bodies, consumer and patient organisations, labour unions and others have begun efforts to gather and report information on quality, although less is being done in the long-term care field.

Arguably, what is needed now in the USA - and in other countries - are consistent measurement and communication tools which can maximise public and private efforts to promote accountability. One part-HCFA-funded organisation, the Portland-based Foundation for Accountability is pulling together information to help consumers make decisions regarding health care. Quality needs to be addressed at different levels, eg institution, provider and managed care organisation.

### **A.1.5 Service delivery models**

One of the most positive and striking things about the US LTC environment is the flourishing number of really innovative service arrangements in spite of, and perhaps because of, the complexity and problematic nature of the financing system.

#### **1.5.1 Care delivery models**

Most long-term care in the USA, as elsewhere, takes place in institutions: around three-quarters of the cost of long-term care is incurred in institutional settings. The de-institutionalisation movement in the 1930s largely eliminated the equivalent of UK 'Part III' (ie local authority-run) residential homes - against which social security was also biased - and spawned the forerunner of today's private nursing homes, which were often individual homes, offering 'family-foster' placements. Adult foster-care homes are the modern survivors of this care tradition.

Despite the pro-institutional incentives built into existing Medicare and Medicaid legislation, institutionalisation rates are currently steady or falling. Various factors may be responsible for this ahistorical reduction: possible declines in age-overall disability rates; the huge increase in the availability of Medicare home health; informal care provision holding up (possibly due to the greater longevity of men); the increased availability of funding for assistive devices aiding aging in place.

Most older people in the USA are either insured and participate in the fee-for-service medical system or, increasingly, are members of a Health Maintenance Organisation (HMO). Both of these models have a medical orientation, and neither provide good long-term care coverage, except for the small minority with the means to purchase as much social care on the open market as they need. Nursing home care, and an increasingly large amount of home care, is therefore funded by Medicaid or individuals themselves.

Of more interest to examination of the boundary between health and social care are three contrasting US models (see examples of two of the models in the Best Practice section) and state programs which cater for chronically ill and more dependent older people:

the Programme of All-inclusive Care for the Elderly (PACE);

the 'Partnership'/Community Options model;

Social Health Maintenance Organisations (SHMOs).

## The PACE model

PACE - The Program of All-inclusive Care for the Elderly - is essentially a managed care system for the very frail older population group. It is a replication authorised by Congress of the fully-integrated managed care system pioneered by On Lok Senior Health Services in San Francisco, California. The first PACE replications began operating in 1990, nearly 20 years after On Lok was founded. The philosophy of the model is centred around providing autonomy and quality and coordinated and cost-effective care.

With assistance from the Robert Wood Johnson and John A Hartford Foundations, the programme is now being replicated nationally. In August 1997, the Balanced Budget Act established PACE as a permanent provider under Medicare and allows states the option to pay for PACE services under Medicaid. The legislation allowed a steady expansion of the model by raising the cap on non-profit PACE programs from 15 to 40 in 1998, with an additional 20 each year thereafter.

PACE allows the pooling of Medicare and Medicaid funds, along with special grant money for administration, to provide acute and long-term care services for the frail elderly with care provided and coordinated by an interdisciplinary team. In the late 1990s, over 70 organisations were exploring, actively developing or operating under the PACE model. Twelve sites have Medicare and Medicaid waivers and to receive fixed monthly capitated payments, allowing them to provide complete care to a nursing home-certified population, including day health, hospitalisation, transport, meals and in-home services. 14 organisations deliver services under Medicaid capitation arrangements.

A PACE organisation can provide care across the whole spectrum of health and social-care interventions. The range of services available to a client of the programme includes case management, hospitalisation and nursing home care if required, physician visits and appointments, prescription drugs, rehabilitation services, extended home-care nursing, social services intervention and respite care. Crucially, the programme enables a single entity to be responsible for the care of elderly people using integrated health and long-term care financing.

The PACE hallmarks are day care, physicians employed by the organisation and a limited choice of providers. An interdisciplinary team assesses, develops and provides care at the day health centre and at home as needed. Besides doctors, nurses and social workers, the team includes day health centre supervisors, home care workers, nurse practitioners, occupational therapists, drivers, dieticians and recreational therapists.

PACE has a small client market - they must be eligible for both Medicare and Medicaid, certified as being eligible for nursing home care and live within the requisite catchment area. At the end of 1996, a little over 4,000 clients were being served in PACE settings. The average PACE enrollee is 80 years old, dependent in 3 activities of daily living, with 8 medical diagnoses. Half of this population are incontinent and more than two-thirds suffer from mental disorders, including dementia and depression.

The true cost of PACE care has not been well described and the provision of housing is an important element of care. PACE sites take on the financial risk for the care needed by its enrollees. To finance this care, PACE organisations receive multiple funding sources, including monthly capitation payments from Medicare and Medicaid for all eligible enrollees. Charges vary according to the state rules governing the PACE site, but generally, there is no charge for people who have both Medicare and Medicaid coverage and co-payments are usually demanded from those with only Medicare coverage.

The costs of caring for such a dependent population are bound to be high. The Medicare payment is adjusted to reflect the higher-than-average frailty of the PACE population (set at 2.39 x payment to TEFRA HMOs). In 1996, the median Medicare capitation rate was a little over \$1,000 per enrollee per month, with a range of just over \$800 to over \$1,750 depending on location. The median Medicaid capitation rate was \$2,137 per month with a range of nearly \$1,500 to \$4,000. The methodology used to set PACE remuneration is designed to guarantee Medicare and Medicaid at least a 5 per cent and 5% to 15% saving, respectively, compared to payers' costs in the fee-for-service system for comparably frail individuals. But it is not clear that actual savings of this order are achieved. Among other factors, savings to Medicare depend on how well the rate is pegged.

### Strengths and weaknesses of PACE

PACE has many positive features. These include:

a one-stop service using integrated financing. The provision of coordinated lifetime care is a real advance over the standard care options - nursing homes, etc - which are available to most elderly people. Care providers bear the financial risk over the capitation payment;

reduced hospital use. There is evidence that PACE enrollees make lower use of hospitals and have shorter lengths of stay in hospital than the Medicare population as a whole, although more use is made of skilled nursing facilities;

specialised and multi-disciplinary care. PACE sites employ physicians who are trained and specialised in older people's health care, and the PACE philosophy is based on the notion of multidisciplinary care.

Its (less well publicised) downsides are:

high costs. With an annual public sector cost per enrollee of nearly \$42,000 for dual eligibles, the costs of PACE care still seem high compared to best international practice for looking after this population;

it has a limited market. The programme is only really attractive to the destitute or low income elderly, as middle-income seniors who are not eligible for Medicaid are understandably reluctant to pay an average of \$2,400 a month for community long-term care;

it serves only a tiny population. The number of people enrolled in PACE

projects at around 4,500 and growing at around 5% to 10% per annum is still very small compared with other managed care systems;

it is a medically-based care model. Clients are typically brought to a centre and returned home at the end of the day. Only around a quarter of the budget is spent on home care, giving care in people's own homes. The On Lok model - originating as it did in the Chinese community in California with its traditions and values - seems somewhat paternalistic and institutionalised.

### Comment

Three PACE sites - two in California and one in Oregon - were visited. PACE has been a relatively successful innovation on the US health-care scene for the very dependent elderly, and this model provides a successful financing and clinical model on which to build. On Lok and other models based on PACE have helped to pilot a care model which is genuinely multidisciplinary and significantly more community-based than that under typical fee-for-service care, which generally implies nursing home care for the most dependent.

The quality of care in PACE settings is also often high. An HCFA-supported evaluation found that PACE care seems to be associated with improved health status and greater confidence in dealing with problems. The concentration on a highly dependent population group and the multidisciplinary input means that the care provided is more likely to be 'holistic'.

But there are several operational caveats with PACE. First, the model is so resource-intensive, especially in its use of adult day-care programmes, that it is limited in the number of people that it can serve. The entire population of the PACE programme is still less than a quarter of the enrollment of the original Social HMOs, which limits its relevance and policy significance. Since it is a demonstration programme with the associated publicity and commitment from staff, the quality effects would be likely to be more muted in mainstream use, even if it were feasible to expand the model.

Second, the geriatric multidisciplinary team at the heart of PACE'S approach is difficult to organise and run - geriatricians are scarce and the egalitarianism of the team seems to make it difficult to retain physicians. Third, the 5% to 15% cost savings over the fee-for-service (FFS) model are not that impressive, given the acknowledged high costs involved with the FFS model, which has strong incentives to over-service. PACE has also yet to solve the problem of financing long-term care for the middle income elderly population and so attract a sizeable private pay enrollment.

### **States' attempts to build on the PACE model**

The more progressive states are aware that broader strategies than PACE and SHMO are required to target the whole population. Realising that demographic trends will place immense pressures on already strapped state resources, they feel they cannot afford to wait until more efficient care delivery systems are developed and are 'pushing the envelope' to find more creative ways of serving the chronically ill population. Several states - eg Minnesota, Arizona and Colorado - have tried to

solve the coordinated care problem at a state level by developing systems which have the capacity to serve large numbers of dual eligibles with varied needs. The Minnesota programme is described in the Best Practice section of this chapter. The Arizona Health Care Cost Containment System (AHCCCS) is a state-wide demonstration project that finances medical services for the Medicaid-eligible population through prepaid contracts with providers. In 1989, the Arizona Long Term Care System (ALTCS) programme grafted Medicaid long-term care services onto the existing AHCCS programme. Under this model, the state contracts with one entity in each county to assume responsibility for services to eligible seniors and physically disabled people. As with PACE, etc, participation in the program is limited to individuals who are certified to be at risk of institutionalisation. ALTCS covers acute services, as well as care in nursing facilities and community-based services, although Medicaid's role in acute care is limited, basically including only cost sharing on acute care and the cost of prescription drugs.

Minnesota is exploring two options for generalising the PACE model. The first method is to 'piggyback' Medicaid managed care contracts operated under waivers onto Medicare+Choice risk plans and to encourage separate enrollment in both products under one HMO. The second model is to merge Medicare and Medicaid contracting and payment requirements under the same waivers as PACE. The latter is seen as easier as it allowed the state to consolidate all the Medicaid and Medicare managed care requirements into one contract managed by one entity at state level. It essentially amounts to a financial merger with no infrastructure changes.

In an illustration of the difficulties inherent in the US medical and long-term care system, the problems associated with trying to bring Medicaid managed care and Medicare plans together include:

the Medicare plan market is highly volatile, is risk averse with respect to long term care costs and has patchy geographic coverage. Benefit rates and premiums may also change with market trends leaving states trying to develop models on a very unstable base;

Medicaid and Medicare may not be able to contract with the same plans as their plan requirements are different;

Federal regulations and administration (enrollment requirements, payment schedules, marketing, grievance procedures, etc) differ between Medicare and Medicaid leading to conflicting requirements and duplication of effort;

traditional Medicare plans may lack the special expertise needed to deal successfully and appropriately with the needs of a chronically ill population.

#### The long term-care state partnership model

Various states, including Wisconsin, have received a grant for the Robert Wood Johnson Foundation to develop and implement a managed care model which will integrate acute and long-term care through community-based organisations (see discussion of Wisconsin Partnership programme in Best Practice section). This model departs from the PACE model by not requiring day centre attendance and



mandatory registration with the organisation's physician.

Care is, like PACE, provided by a multidisciplinary team, and the elderly person retains the use of their own physician who could be employed by an HMO, hospital, clinic or private practice. A network of small, focused programmes exists under the overall management of the Partnership programme. In contrast to PACE, the Partnership model is committed to bringing services to people in their own homes. This latter way of working is generally thought to be more consistent with the preferences of the elderly to live at home.

One aspect of this approach is that there is a need to create an effective 'bridge' between the primary physician and other team members. A senior nurse - nurse practitioner - usually plays this role.

### **Social Health Maintenance Organisations**

Social Health Maintenance Organisations (SHMOs) extend the concept of health maintenance organisations by including certain long-term care services not normally covered in traditional plans. Initially conceived by researchers at Brandeis University, Medicare/Medicaid demonstrations have been in operation since 1985.

Three of the initial four demonstration sites are still running. These are: Senior Advantage II in Portland in Oregon; ElderPlan in Brooklyn, New York and SCAN Health Plan in Long Beach, California. SeniorsPlus in Minneapolis, Minnesota, was the fourth initial demonstration site. The site in Oregon is sponsored by a large ongoing HMO (Kaiser Permanente), while the latter two are sponsored by long term-care organisations. Enrollment on the programmes is around 17,000 - significantly larger than the PACE experiments.

The 1991 Omnibus Reconciliation Act called for HCFA to establish a second generation of SHMOs. In early 1995, sites were chosen in the following locations: Columbia, South Carolina; Coral Gables, Florida; Grand Junction, Colorado; Las Vegas, Nevada, and Worcester, Massachusetts. SHMOs have only a limited range of LTC benefits, and the two 'generations' of model are quite different. The first generation model focuses most attention on the nursing home eligible population, while the second-generation models have a broader focus and attempt to provide more integrated care.

The initial SHMO sites have four main organisational and financing features:

- one organisation provides a full range of acute and LTC benefits to Medicare beneficiaries who voluntarily enrol in the programme and pay a monthly premium for services (dually eligible beneficiaries may also enrol). Medical care is provided by physicians at the HMO medical centres and hospitals. Medical benefits include all Medicare benefits, plus prescription drugs and preventive services;

- the financing mechanism involves pre-paid capitation, pooling funds from Medicare, Medicaid, member premiums and co-payments. Long-term care and expanded acute care benefits are funded through premiums, co-

payments and acute care savings - not additional public payments. Coordinated care and case management systems authorise long-term care benefits for eligible persons. Case managers are advocates, assessing the need for care, planning and arranging services, as well as gatekeepers, controlling the amount of resources used;

fairly tough cost monitoring and control. While SHMOs provide coverage for a range of long-term care services that are not covered under Medicare or Medigap policies, the sites have attempted to contain costs within a cap of \$7,500 to \$10,000 per person per year (mid-1990s prices). They do not cover extended-stay nursing home care or long-term highly intensive home care.

SHMOs have sought to overcome the traditional communication difficulties between medical and long-term personnel in innovative ways. Three main channels\_of communication are used. First, the SHMO Director regularly attends case conferences with the case managers, communicating with other physicians about long-term care issues raised. Second, referral and communication links have been established between physicians, social services staff, home health-agency staff and case managers. Third, at all sites, medical records are available for review by case managers, and care plans are available and shared with medical staff.

One of the organisations (Seniors Plus) developed an effective one-page summary home-assessment report linking the primary care physician (GP) and case manager input. After each in-home assessment, at least every 6 months, the report is updated by the case manager and transmitted to the GP. In turn, each time the GP updates medical treatment or medications information, the form is transmitted to the case manager. This process informs the GP about functional problems at home, the family support system and how these are being addressed.

### Strengths and weaknesses of SHMOs

The main advantages of the SHMO model are:

**risks are pooled** by enrolling a lot of people, alongside the disabled, who are not disabled and are unlikely to make heavy use of services;

as a result, **premiums are much lower than in the On Lok/PACE model** (which has an exclusively and heavily disabled population);

lower premiums allows the SHMO to **enroll people with moderate incomes** and not just the Medicaid-eligible population;

SHMOs can be **responsive to people with short-term disabilities** or who need help with recovery or skilled and supportive services beyond those traditionally covered under Medicare.

The SHMO model has several disadvantages:

the **level of long-term care benefits has been fairly modest** (\$6,500 and \$12,000 per member per annum). In order to keep premiums down and to

compete with other HMOs, the amount of nursing home coverage has been particularly limited. Wiener classes SHMOs as Cadillac-level Medigap insurance, rather than full long-term care insurance;

there is a **danger of 'adverse selection'**, with organisations under pressure to select clients with relatively mild disabilities. Initially, to minimise this effect, HCFA insisted on a quota-type arrangement whereby clients can only be placed on a waiting list once a given number of disabled people enrolled. Early data showed that 50% of the patients under case management had two chronic conditions and a third were 'medically complex';

SHMOs have found it **difficult to provide distinctive services** for the relatively small number of enrollees with severe disabilities due to the limited economies of scale in provision.

### Comment

The SHMO experience has an encouraging message: namely that mild to moderately functionally disabled people can be maintained for long periods of time in their own homes, even when their informal support systems are not strong. In this sense, provision of case management and expanded community care seems to work. Proponents argue that the costs of expanded community-care plans have been well within SHMO benefit limits (\$6,500 to \$12,000 a year), which in turn are much less than community-care cost estimates for most Congressional LTC proposals - eg the Pepper Commission proposed a monthly service cap of \$1,620 (\$19,500 a year), compared to an average SHMO monthly cap of nearly \$700 for a similar benefit.

## **The 'Cash and Counselling' Direct Payment Demonstration Program**

As the cost of long-term care has continued to rise (eg a 9% increase in Medicaid spending in 1997/98), policymakers have sought new models to control costs while maintaining or increasing consumer satisfaction. One innovative programme is being sponsored by the Robert Wood Johnson (RWJ) Foundation and the US Department of Health and Human Services.

The RWJ Foundation has co-sponsored a model of consumer-driven care called the 'Cash and Counselling' programme in 4 states (Arkansas, Florida, New Jersey and New York). In the programme, information and training are provided to participants along with cash allowances that are paid directly to them, allowing them to purchase the services they feel best meet their needs. Up to 20,000 people are taking part in the programme, and RWJ are funding the core administrative costs (\$2 million per state) and \$7 million of Federal money is earmarked for evaluation. Total funds flowing through the programme may amount to upwards of \$100 million.

Consumer-directed care is arguably one of the most significant innovations in long-term care in the 1990s. The philosophical basis of 'consumer direction' is consistent with the goal of independent living expressed throughout the Older Americans Act.

including Title I, which states that service-providing organisations are responsible for helping older people secure the "free exercise of individual initiative in planning and managing their own lives" and "full participation in the planning and operation of community-based services provided for their benefit".

So how does it work? Traditionally, agency-directed services have the following features: care delivered by a provider agency; case management to coordinate services, and public regulation of providers to assure quality. Service decisions tend to be based on the judgements of the case manager or provider agency staff. Consumer-directed services, by contrast, are intended to allow informed consumers to assess their own needs, determine how and by whom these needs should be met and monitor the quality of services received.

Typically, in consumer-directed care, personal care services are provided by a home care worker who is selected, trained and supervised by the consumer. Cash and Counseling (C&C) is one of the ultimate forms of consumer direction in which the consumer is given the option of receiving cash payments that they may use to purchase a variety of support services. The consumer has the flexibility to choose the way they want to meet their needs for personal assistance, within certain rules. They may purchase home-care services from a home-care agency, an adult day-care centre, a friend or a relative. They may also use the money to make home modifications or buy assistive devices to limit their need for future care. The unifying principle is that individuals have primary authority to make choices that work best for them.

A number of states, including Michigan, Wisconsin and Colorado are currently using state funds to make C&C one feature of their LTC systems. The model, or a variant of it, is being tried in the Netherlands, Germany and Austria.

The most attractive features of the programme are:

the autonomy and decision-making power of consumers is increased;

C&C allows an existing family member or friend to be reimbursed;

it allows individuals and their families to design and control services precisely to their own needs, potentially delivering more seamless care.

An evaluation of the Californian programme showed that, overall, clients preferred the consumer-directed care model, though the provider agency model satisfied clients with relatively moderate needs. The interpersonal and other benefits of receiving services from a family member seemed to outweigh any possible shortcomings in technical skills.

### **1.5.2 Housing models**

#### **Nursing homes**

Nursing homes are the best-known group, residential option for older people with disabilities who need ongoing care. Powerful interest groups of providers exist to

promote this type of care. However, talking to older people and their advocates makes it clear that nursing homes are dreaded by almost all potential residents.

People fear they will be labelled as 'patients' and that admission will result in loss of autonomy, privacy and identity; possibly unresponsive or poor care and impoverishment. To allay some of these concerns, the regulation of quality has become a perennial preoccupation for state and Federal governments. As nursing homes are designed, operated and heavily regulated as health facilities, they are in a poor position to innovate and test non-medical approaches to care.

### Residential care (board and care) facilities

The USA has a wide variety of residential options other than nursing homes. These go under various generic names: board and care homes, residential care facilities or adult care homes. Other terms used include assisted living, rest homes, continuing care communities, personal care homes, domiciliary homes, retirement homes, family care homes, adult congregate living facilities and many others. These settings vary from those that serve people with Supplementary Security Income (means-tested income assistance for the aged, blind and disabled) level incomes to those that serve the affluent.

Board and care homes usually cater for people with psychosocial needs rather than physical disabilities. These homes typically provide housekeeping and meals and may provide some protective staff oversight. The distinguishing feature of most of these homes is that they are not set up to provide a comprehensive range of services or meet unscheduled needs. Upmarket private homes, which cater to a very different market, however, generally operate under the same state licence as board and care homes and may also discharge residents who become more disabled.

Congregate care - in complexes with separate apartments and some hotel services, eg housekeeping and one or more group meals - also exists along similar lines to European models as, for example, in the Netherlands, eg Humanitas.

Continuing Care Retirement Communities (CCRCs) cater for disabled older people and have three levels of care corresponding broadly to the models of independent living, assisted living and nursing home care. They are not models that work for the very disabled. There was initially concern about the fees charged by such establishments and their financial viability. Although regulation has largely solved these problems, there are still concerns about the potential loss of control inherent in joining a complex with ever-higher levels of care and the risk of placement in an outside nursing home if there is not space at the required time in the CCRC itself.

Adult foster homes or family care homes are not widely developed and tend to serve the mentally ill and handicapped populations rather than the elderly and those with physical disabilities. In most states, the programmes are targeted at low-income people. Oregon is the only state in which adult foster care is a mainstream option for the functionally impaired.

There is growing interest in the USA in new ways of meshing services with housing. US housing authorities have only recently paid attention to services, and long-term

care agencies have tended to ignore the fact that a nursing home programme is, at least in part, a housing programme. Simultaneously, analysts and commentators have recommended that housing designs take service needs into account and that, for payment purposes, the board and lodging component be separated from the care component.

## **Assisted living models**

The Federal Government is now clear that it wishes to allow more home and community-based alternatives to institutional care. There is a desire to promote more diversity in residential settings besides nursing homes, which cater for the older, more disabled elderly and provide more integrated or seamless care. With Federal Government support, various sheltered living models are being experimented with in different parts of the country, eg continuing care residences, personal care homes (Pennsylvania), assisted living facilities (Minnesota and elsewhere) and adult foster-care homes (Oregon).

Assisted living is one model that is amenable to thinking creatively about the separation of housing and care discussed above. In assisted living facilities (ALFs) older people who are technically eligible for nursing home care can receive personal care in fairly normalised and home-like settings. There is almost no involvement by the Federal Government in ALFs. The further development of the assisted living model may depend on a relaxation of the previous rules concerning the provision of services in public housing and a separation of payment for housing and services.

ALFs are an innovative US concept encompassing housing and care for frail older people as well as for disabled persons and are one of the fastest growing segments of the housing market for older persons. The average size of an ALF in the USA is 35 to 40 apartments and the average cost of a place is around \$22,000 a year (around £280 per week). The typical ALF resident is an 84-year-old woman who needs assistance with 3 ADLs (activities of daily living - washing, dressing, bathing, etc). The average length of residency is 2/4 years.

Since the 1980s, the emergence and rapid development of ALFs has given frail older persons and people with disabilities another option for meeting their personal and supportive care needs. The state of Oregon pioneered ALF development which offered home-like residences as an alternative to nursing home care. Many states are currently developing an ALF regulatory structure. Assisted living is currently being helped by the fact that it is attractive for states to house people in such homes as more of the costs can be met through Medicare (home health). HCFA, however, is trying to deny payment for these costs on the grounds that they are covered within the basic ALF fees.

What does an assisted living facility look like? It is a residential setting that provides or coordinates personal care services, 24-hour supervision, scheduled and unscheduled assistance, social activities and some health-related services. An ALF provides a home-like atmosphere and is designed to minimise the need to move by accommodating residents' changing care needs and preferences.

One of the advantages of the ALF concept is that the housing and care service components can be separated. Private rooms are the preference of the vast majority and are the norm (86% of residents were living in private rooms in 1996). The rooms typically have food storage capacity and bathing/toilet facilities. Many newer ALFs provide private apartments or studios.

Around half have cognitive impairments (dementia, etc). There is a lot of variation in AL. ALFs offer a range of services that can be tailored to meet residents' individual care needs. Virtually all sites offer: assistance with activities of daily living (eg dressing and bathing), 24-hour supervision and security, three meals a day, housekeeping, laundry, social activities and an emergency call system. Personnel regulations - eg the extent of nursing delegation - are an important factor.

AL homes lie somewhere on the care spectrum between a luxury sheltered home and a skilled nursing facility. At one end, deluxe residential facilities cater for people with low-care needs (screening will be important here) and the emphasis is on staff-client ratios and the provision of scheduled care. At the other end, the facility is essentially a replacement for nursing homes and the residents' greater needs as a result of aging in place mean that the homes operate in a more regulated environment. However, assisted living is not generally appropriate for persons needing 24-hour skilled nursing care or ongoing medical monitoring.

The philosophy of assisted living emphasises personal dignity, autonomy, independence and privacy. The objective of assisted living is to maintain or enhance the capabilities of frail older persons and persons with disabilities so they can remain as independent as possible in a home-like environment. To a certain extent, assisted living also enhances a resident's ability to 'age in place' by providing services that intensify or diminish as a resident's needs change.

The costs of assisted living vary dramatically - from \$20 a day to over \$200 a day at the top end. The typical daily rate of an ALF is less than a nursing home rate. The average daily rate for a private room was \$72 (\$2,200 a month), compared to a nursing home rate of \$127 a day or \$3,800 a month. For those with low incomes, a few states are incorporating ALFs into their public LTC systems, typically through a Medicaid home- and community-based services waiver, which covers the services portion of an ALF stay. Low income persons who are eligible for Supplemental Security Income can use those funds to subsidise room and board costs.

'Acuity creep' in assisted living settings will raise costs over time. The medical component of care will become more important as people age in place. Aggressive medical treatment will be needed to deal with episodes of acute illness, although it is only likely to be cost-effective in meeting relatively light needs in assisted living settings.

### Strengths and weaknesses of the assisted living model

Assisted living models look promising for three main reasons:

a majority of older persons have consistently indicated a desire not to move to

an institutional setting even when they can no longer live alone. Assisted living facilities can meet this preference by combining a residential atmosphere with appropriate individually tailored services;

assisted living gives older people another option. It provides a useful link between sheltered homes such as continuing care residences at one end and more traditional nursing homes at the other end of the care spectrum;

they might offer higher quality care than nursing homes are able to, in a more person-centred care environment. They also hold the promise (through public subsidy) of being able to house the less well-off, as well as the more affluent.

Difficulties with the assisted living model include:

its relatively high cost. So far, assisted living has been marketed to the more affluent in the USA, although as the elderly get richer with higher occupational and personal pensions, more people are likely to be able to afford private-pay homes. In future, multiple private payers may be able to cross-subsidise the provision of places for publicly supported clients;

the issue of a negotiated level of risk. There are real difficulties to be negotiated in trying to respond to individual needs for autonomy while meeting legitimate regulatory requirements and the family's concern for safety.



## A1.6 Broad Policy Debates

The complexity of the US care delivery system structure makes it extremely difficult to implement seamless care for the elderly and mentally ill, except for the small minority who can pay the full cost of all their care regardless of the cost. In some ways, the US system could be described as embodying the worst of both worlds: discontinuous and relatively expensive private provision alongside high and growing public costs. One analyst has commented: "no other part of the [American] health care system generates as much passionate discontent as does long-term care" (J Wiener, *Brookings Review*, spring 1994).

Surprisingly, though, there is more discussion about the health and social services boundary in the UK (where the system is less unsatisfactory) than in the US. The orientation towards choice and fee-for-service providers is attractive to consumers, and the legislative process combined with strong pressure groups conspires to sustain the status quo. However, neither the fee-for-service system nor the expansion of public funding is likely to solve the finance and delivery problems of long-term care. Much discussion therefore revolves around ways to improve care within existing resources and constraints.

Most policymakers and commentators agree that the boundary between health and social care should be softened, if not eradicated. Historically, Medicare has been designed and seen as a medical programme and hence has not provided enough care at the 'softer' end, ie for long-term care. There is sympathy to the view that people come with a variety of acute and chronic needs and need to be treated in a more unified fashion.

Three broad issues dominate the US health care debate:

**cost containment**, with a search for ways, including managed care and private long-term care insurance, to control costs;

problems of **access, quality and fragmentation of care** have led to a search for better care and service models;

the **problems associated with cost-shifting** between the Federal and state layers of government.

### 1.6.1 Cost containment

The Government has focused hard in recent years on controlling costs (see The Strategic Framework in section A1.2). Talking to Congressional staffers and the Congressional Budget Office (CBO), it is easy to come away with the impression that it is costs - not coverage, quality or prevention of illness - which is the dominant health policy issue. This is probably an excessively narrow view, but nevertheless the sheer costliness of the health system is striking - costing around \$1,100 billion a year or 13.5% of GDP.

Arguably, this need not be seen as a problem if the \$1 trillion plus expenditure is overwhelmingly private spending - after all, the Government does not worry about household purchases of entertainment, IT equipment or food, whose costs are all borne privately. Unfortunately, though, public programmes account for nearly half of total health care spending (over \$500 billion). Federal and state governments purchase health care for over a quarter of Americans through both Medicare, the Federal programme of medical care for the elderly, and Medicaid, which meets long-term care costs for the poor.

Costs reflect this role. The latest HCFA estimate shows that, with increasing long-term care costs, Medicaid spending is catching up. These public costs have risen dramatically in the last 30 years and are now an important source of fiscal pressure on the Government. Public health programme spending grew from nothing in 1965 to \$160 billion (two-thirds on Medicare) in 1985 and more than doubled again in the following ten years. Medicare and Medicaid spending was \$215 billion and \$160 billion respectively in 1997 - a combined total of \$375 billion - almost 35% of the cost of all health care spending.

#### Projected care cost increases

This growth paints an ominous picture for the future. On current policies, as the US population ages and dependency levels rise, the costs of care and, in particular, nursing home provision will rise. Since about two-thirds of those in nursing homes are in receipt of Medicaid, public costs will rise steeply as the 'baby boom' generation (born in the years 1946-64) reaches advanced old age (over 85 years).

Not surprisingly, given the increased need for LTC and the domiciliary care emphasis, Medicaid and the Medicare Home Health programme are the main cause. Medicaid long-term care spending increased by over 10% per annum in the first half of the 1990s, and has grown slightly more slowly in recent years. Real spending growth in Medicare and Medicaid ran at 6.3% and 4.5% respectively in 1995-96, significantly faster than real GDP growth of 2.8%. Spending has picked up an even faster pace recently.

The latest data shows that Medicaid spending for LTC rose by 9.3% from 1996-97 to 1997-98 - the highest rate of increase in LTC spending since 1992-93. The cost of the Medicare home health programme (see section below) has also risen sevenfold over the last ten years. While costs are probably rising slower than in the late 1980s, care expenditures are probably still outstripping GDP growth.

Even if current pressures were not worrying enough, lobbyists for the elderly and disabled have sought to extend federal and state-level support and benefits, in the face of substantial unmet needs and concerns about quality of care. On the other hand - mindful that the current Budget surplus conceals a large surplus in the Social Security Fund which is due to evaporate in the early years of the next decade - Congress has become very wary of approving new spending. It remains concerned about demographic trends and the potential growth of long-term care costs.

here is a deep-seated, and partially justified, worry that if the system is liberalised, eg by more generous funding for home care or an expansion of eligibility for Medicaid,

there will be a 'woodwork' (dead-weight cost) effect, whereby care that was previously provided by relatives and voluntary sources will be replaced by public funding at great expense.

### Rapid growth in home health care costs

Traditionally, home health care had to be authorised by a person's physician and had to be purely medically-related. Home care benefit had also been classified as a Part B benefit, with larger co-payment fraction. Nevertheless, since 1989 there has been a rapid rise - three or four-fold - in the use of Medicare home health services as a result of a ruling which allowed Medicare coverage for home nursing care and assistance with bathing and dressing. As a result, Medicare will now pay for up to 200 to 300 visits a year.

This is a prime area for cost shifting. States are now waking up to the fact that Medicare should pay for home health services. The fact that Medicare home health care expenditure has been rising at 35% per annum, while recent rates of growth of Medicaid home care have been below the rates for nursing home spending, show they have been succeeding. Changes to medical eligibility rules for nursing home and home health coverage have meant that expenditure has risen from \$3 billion in 1988-89 to \$20 billion in 1998-99.

This increase in Medicare expenditure has led a concerned Congress - spurred by Balanced Budget legislation - to lower payments for home health care and reduce eligibility. Payment rates were based on 1994 utilisation levels, which have caused a contraction in the home health sector. As a result, home health spending has been reduced and now stands at about \$17 billion.

But this has a clear downside and is generating a public backlash. Carers organisations point out that, increasingly, families and other carers are having to handle the type of post acute care (including intravenous injections or complex equipment) that would traditionally have been provided by formal care services without proper assessments of carers' ability to cope. Carers are faced with a 'Hobson's Choice' of the worry of looking after the relative, the expensive cost of formal care in a (depersonalising) nursing home or inadequate care.

### Long-term care insurance

Long-term care insurance has been seen - particularly by the political right and those who are inclined to view health as an individual responsibility - as the saviour to the cry that care costs are rising too fast. But, convincingly, researchers at the Urban Institute have shown that expansion of private long-term care insurance does not hold the answer to meeting America's long-term care funding needs.

Reliance on private LTC insurance faces a number of severe obstacles. None of the problems individually pose a deathblow to the concept, but collectively they are damning:

private care insurance policies are very expensive (and allowing adequately for inflation would make them even more expensive), and the companies are

not willing to make them cheaper without public financial support;

as a result, the policies are not popular. In a positive environment for private solutions and, despite a very hard sell (through an intensive public advertising campaign), the number of Americans taking out private LTC insurance has only reached 8% of potential enrollees. Research shows that those who do take out policies do so not to protect assets (the dominant advertising message), but to preserve their autonomy in later life;

most serious in terms of viability, none of the policies on offer qualify for Medicaid top-up funding.

Even if everyone purchased long-term care insurance (and only 5% currently do so), it has been estimated that this would only cut the Medicaid bill by 25%, due to exclusions and limitations on care provided through insurance.

Therefore, any viable widespread long-term care insurance system would require public backing to spread the risks associated with the very costly, but difficult to predict incidence of long-term care. In any case, some social insurance, for those on low and very low incomes, would almost certainly be required as part of any LTC insurance scheme. This inevitably entails additional public spending and poses a severe obstacle in a spending-hostile Congress.

### **1.6.2 The quality and fragmentation of care**

Perhaps the most serious problem facing consumers is the costliness of care due to repeated hospital stays (although US hospital stays are shorter than in most countries) and the fragmentation of care providers. Although the dual eligible population (those entitled to Medicare and Medicaid) - ie the poor and sick - are frailer, poorer and have more chronic diseases, they receive more fragmented and thus expensive care.

County and state health workers, providers who work with the elderly and consumers, have long identified conflicts between Medicare and Medicaid policy and financing. The needs of the elderly do not fit neatly into existing acute- and long-term care boxes. It is not uncommon for older people with chronic care needs to require a large number of services at the same time. Accessing services from two or three different systems with different rules, case managers, ID cards/numbers, telephone numbers, etc, can be very difficult for older people.

Apart from the problems discussed below (quality, cost shifting, etc), particular problems with the US system include:

**a fragmented clinical system.** Each hospital, nursing home and home care agency does its own independent case management. Communications links between long-term care providers and hospitals, clinics and the doctors who manage acute care services are often lacking. There is often poor coordination between the acute and long-term care systems.

**poor incentives.** The Medicare fee-for-service payment schedule pays

doctors more to treat the elderly in hospitals or clinics instead of in a nursing home. Medicare risk plans are paid more for placing older people in nursing homes, with substantially lower payments for community-based care. Medicare also pays doctors and other health care professionals nothing for working with families and community services to keep people in their own homes and prevent unnecessary nursing home placements;

**excessive administrative costs**, due to different regulations. Health care providers are required to duplicate paperwork and send one bill to Medicare and another to Medicaid for the same service. People who are dually eligible receive a large amount of confusing paperwork from Medicare, even though Medicaid is paying for their co-insurance and deductibles.

### The use of managed care

The most difficult issue in delivering more integrated care has been how to bring the financing streams together and thereby change the way services are configured and delivered on the ground. Employers, through HMOs, eg Kaiser Permanente, and a few pioneering states such as Wisconsin and Minnesota have tried to integrate the provision of acute and LTC services through managed care.

Besides immense bureaucratic obstacles, these attempts have been greeted by scepticism from some in the medical community (including physicians who might see a threat to their income from the fee-for-service system) and challenges from advocates and providers of care services. Concerns tend to centre around:

whether an integrated acute and long-term care system would be dominated by acute providers;

the fact that managed care providers have little experience of dealing with the elderly.

Nevertheless, managed care has taken off for acute care, although not for LTC. Two problems have held back the progress of managed care organisations:

people's concern to have complete freedom of choice of providers and to get care quickly when required - both of which conditions are apparently satisfied by the fee-for-service model. Managed care organisations (MCOs) typically limit coverage to care provided through a direct provider network. This is seen as constraining peoples' choice. Furthermore, companies can and will change MCOs in order to get a more competitive fee quote, imposing further changes in providers on consumers;

the acute medical, rather than chronic care, focus of managed care. Another aspect of this problem is that the risk pools for HMOs are often not big enough for them to be able to deal with high cost outliers, which are a feature of providing care for the elderly.

### Quality of care

The importance of the profit-motive in US healthcare, and the commensurate focus by providers on costs, has led to, especially in nursing homes, a system that many feel to be over-regulated. The US system of statutory, rather than common, law lays down highly detailed and prescriptive rules for care of the elderly, particularly in high-intensity care settings such as nursing homes. But tight federal requirements do not prevent significant geographical inequity, since states have differing philosophies, funding sources and range of services for the Medicaid-eligible population practices.

A key quality issue concerns the perceived safety of care in an institutional setting or at home. One of the key issues for aging in place is balancing safety and autonomy. A balance needs to be struck between the desire of the individual to stay where they are and for the external world to adjust to their individual preferences and a need to ensure people are adequately cared for and protected.

### Remedying information failures

Organisations such as the Foundation for Accountability (see Best Practice Examples) have pointed out that consumers are often poorly informed about health care choices. One helpful factor here - of as much use to the elderly as other groups - is the fact that America is leading the way in using computer technology in medical care. Advances in computer technology are generating better ways of communicating vital patient information among providers and thereby enhancing health delivery and efficiency.

New communication tools and associated advances like on-line medical records may foster care coordination and better use of existing information, which can reduce duplication of services and the adverse outcomes associated with interactions between conditions and treatments. The Internet - and most subscribers are still American - could facilitate a major shift in the relationship between consumers and their health plans and providers. Besides the potential for more coordinated care by providers, computer technology could also boost consumers' power and lead to demands for a more partnership role in their care.

'Healthfinder' - part of the Internet site of the Department of Health and Human Services has a searchable index and locator for news, publications, on-line journals, support and self-help, toll-free information numbers and links to over 550 sites, including 200 federal and over 350 state, local, non-profit, university, library and other health information sources.

### **1.6.3 Cost shifting**

Hospitals have incentives to admit elderly people frequently - to obtain the Medicare payment - but not keep them for very long. Nursing homes have incentives to send people to hospital for short stays rather than treating the person when acute episodes occur because Medicaid does not directly reimburse the extra care required. Health Plans have no incentive to keep seniors in their own home rather than a nursing home.

As a result of these incentives, it is no surprise that hospital lengths of stay are very (sometimes inappropriately) short. Patients are moved more frequently than is good

for their health between care settings, and few people opt to remain at home rather than go into a nursing home, unlike in the UK, where the opposite has been the case.

Another by-product is that there is rampant cost shifting. Changes in Medicare or Medicaid programmes may shift costs to the other, since many Medicare and Medicaid services substitute for each other. This goes both ways:

Medicaid services - eg nursing homes and home care - are substituted for more expensive Medicare services like hospital care, shifting costs to states. Patients can be shifted into long-term care environments despite having clear residual medical needs;

Individual states try to shift costs from long-term care (eg nursing homes), which they pay in part for by sending people to an acute medical care setting at the slightest sign of medical problems, as the latter is paid for by Federal Government and private individuals through Medicare.

These federal/state practices are the mirror image of the Australian system, where the Federal level (the Commonwealth) has broadly the responsibilities of US states.

The perverse incentives generated by the funding system mean patients may end up in inappropriate settings, with consequent quality of life and health risks. There are also pernicious results in terms of wasted effort and high bureaucratic overheads.

## **A1.7 Best Practice Examples**

### **Example 1: On Lok Senior Health Services (The PACE Programme)**

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The On Lok organisation is the progenitor of the Programme of All-inclusive Care of the Elderly (PACE) - see section on care delivery models in Section 1 - which has spread to include a growing number of organisations over the country. Other functioning PACE sites visited include the Center for Elders Independence in Oakland, California, and Providence Elder Place in Portland, Oregon.

On Lok SeniorHealth now serves an enrolled population of 750 frail elderly through 6 centres throughout the city of San Francisco. The PACE programme (see main text), with On Lok as the model, now serves a population of around 4,500 through demonstration projects operating at over 70 sites in more than 30 states.

#### The history of On Lok

On Lok Senior Health Services (On Lok means 'peaceful happy place' in Chinese) was formed in 1971 to provide community health services for the frail elderly of the Chinese community living in Chinatown and other areas of San Francisco, California. The group took advice from Marie Louise Ansak, a Swiss-born social worker, who had worked extensively with the immigrant population of San Francisco. Marie Ansak recommended a system based on the British model of day hospitals which sought to avoid premature (and unpopular) nursing home placements by providing health and social care services at a day centre, while participants continued living in their own homes.

Grants to establish a free-standing community adult day centre (in an old shop front on Broadway Street) were first received from the Administration on Aging and the State of California Department of Health Services in 1973. Recognising that participants required care after the centre had closed for the day, On Lok added services such as meals, home care and supported housing. In 1978, the Health care Financing Administration (HCFA) awarded On Lok a four-year demonstration grant to integrate medical services with the already established long-term care services.

In 1983, On Lok's comprehensive consolidated service was deemed a success and On Lok obtained waivers from both Medicare and Medicaid to establish a new capitated financing system. As the organisation operated without a loss between 1983 and 1986, these waivers were made permanent in 1985. In 1986, Congress authorised a demonstration to test the replicability of On Lok's approach at sites around the country - this was called the Program of All-inclusive Care for the Elderly (PACE) - see part 1 of this chapter for details.

### Key components of On Lok's care programme

The aim of the organisation is to enable the frail older person to remain in familiar circumstances, maintain their autonomy and preserve maximum physical, social and cognitive function. The service package offered by the organisation includes all Medicare and Medicaid services as well as community long-term care services, with no co-payments or deductibles.

On enrollment at the centre, a participant is assessed systematically by an interdisciplinary team consisting of the primary care physician, nurse, social worker, rehab therapist, home health worker and others. The team is responsible for decisions on service allocation and takes account of the social, emotional and physical factors affecting a person's health care needs. The model prescribes that the team provides a continuous process of assessment, treatment planning, service provision and monitoring. On Lok emphasise center-based services and the use of physicians approved by the organisation.

### Costs

In 1998, On Lok's average monthly Medicare premium was \$1,282 (Parts A & B). Medicaid's payment is negotiated annually with the participating state's health department. On Lok's Payment is based on the state's costs for a nursing home population in San Francisco - in 1998-99, this premium was \$2,213.



## Comment

On Lok has clearly been an inspirational force in a system that is overwhelmingly dominated by institutional care settings and a powerful and vocal nursing and residential care home lobby.

The PACE comprehensive capitated payment model has clear advantages over the fragmented and costly care received in the fee-for-service system. It provides more humane care and enables most clients to carry on living in their own homes. Because it cannot shift costs, On Lok and other PACE organisations have every incentive to manage its financial risk by keeping each programme participant as healthy as possible through aggressive preventive health practices, frequent monitoring of the person's health status and through careful use of resources. The aim of clinical monitoring is to reduce morbidity and mortality and thereby avoid costly hospital stays. Evidence shows that, to a limited extent, the model does this.

However, the care provided by On Lok is based on a medical model - usage of the term 'patient' in promotional literature is revealing - which squares uneasily with trying to ensure that health and social care are integrated. Another drawback is that someone enrolling on the programme has to forego use of their own physician and rely on the centre staff. This denial of choice, together with the centre-based nature of the service, is the main reasons behind (the low level of) disenrollment.

## **Example 2: The Wisconsin Partnership Programme**

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### The History - The Community Options Program

In the 1970s a Supportive Homecare Program existed in Wisconsin. This was not a comprehensive care programme but aimed to help people stay in their own home. The prevailing long-term care arrangement throughout the 1970s and 1980s was characterised by a great bias towards institutional care in nursing homes, with few and fragmented community-based services. Clients were fitted into existing local services rather than services being fitted to meet the unique need of individuals.

The next phase in developing community-based services was the setting up of the (widely emulated) Community Options Program (COP). COP was the product of

nearly three years of collaborative planning by agencies responsible for the long-term care of the elderly and disabled. Wisconsin piloted this Program in 1982 in eight counties and expanded it to operate in all 72 counties in Wisconsin by 1986.

The purpose of COP is "to provide whatever assistance individuals need in order to continue to live in their own homes, in their own communities, at a cost which averages no more than nursing home care". COP provides state funds to match federal funds for services provided under a Medicaid waiver. The programme is a social worker case management model and encourages the integration of the elderly into the community through providing help with performing activities of daily living. Eligibility for COP is based on a state-wide assessment of eligibility for nursing home care (clients with dementia were automatically eligible).

In 1996, 9,400 assessments were conducted of whom 70% went on to develop a care plan. In 1996, nearly 17,000 persons were served with regular COP and/or COP-Waiver funds at a total programme cost of \$132 million including federal matched funds. Success is measured by scheme administrators on two dimensions: first, the production of positive outcomes for participants and second, how well the programme is able to contain the use and cost of Medicaid funded nursing home care.

The combination of a moratorium on state-funded nursing home beds, a stop on funding for high dependency Intermediate Care Facility places and the enactment of the Community Options Program in 1981 is estimated to have reduced the numbers of Medicaid funded residents in nursing homes by 40% less than predicted. This projection was based on existing demographic trends, (downward) trends in custodial care and continuation of previous policies - from nearly 37,000 in 1980 to 31,900 - compared to a projection of 56,300 places in 1996. This reduction in nursing home utilisation is estimated to have resulted in 'hundreds of millions' of dollars (Wisconsin Bureau of Aging) of savings.

However, under COP, physicians did not liaise well with social workers, the delivery of medical and social services were not properly integrated and the state applied for waivers to run a 'Partnership' programme.

### The Partnership Program

The Wisconsin Partnership Program (WPP) developed COP (which is still running) still further, by trying to improve the integration of medical and social services. The WPP is a comprehensive programme of services for people who are elderly or disabled in Wisconsin. The programme integrates health and long-term support services. Home and community-based services, physician services and all other medical care are coordinated by a care team. A key element of the programme is team-based care management, in which the client, their physician and a team of nurses and social workers develop and deliver a care plan together. Services are delivered in the client's home or in a setting of their choice.

Participants in the programme must at least be eligible for Medicaid or 'dually-eligible' for Medicare and Medicaid. They must also meet the Medicaid nursing home level of care requirement. Participation in the programme is voluntary and

participants can disenroll at any time, although contractors may not disenroll participants except under stringent protocols approved by the State Department of Health and Family Services (DHFS).

### Goals of the Partnership

The goals of the Partnership are to:

control health care costs among elderly and physically disabled people who meet nursing home admission criteria. Since it is a PACE variant, cost control depends on how rates are set;

increase quality through integration of preventive, primary and chronic care via the interdisciplinary care model;

improve health outcomes through the delivery of integrated preventive care;

increase the role of the participant in decision-making.

The programme aims to control health care costs for the chronically ill elderly by capitating Medicaid and Medicare funding streams and by providing integrated long-term support and acute care through a managed care system. Capitating various funding streams and providing comprehensive services helps to prevent cost-shifting (since all services are provided under one programme), improves cost effectiveness and provides an incentive to give preventive care. The managed care delivery system tries to deliver an integrated plan for enrolled individuals that limits the use of high cost institutions and specialty services as well as reducing administrative costs.

The aim of increasing quality is primarily met by using an interdisciplinary team model focusing on the points of care intersection where the health care system traditionally breaks down. By coordinating transitions between service providers who normally operate in parallel, they prevent two or more different systems prescribing duplicative or contradictory treatments. By creating a visible, important role for clients, the 'team' is simultaneously made responsible for ensuring quality and managing costs - not simply the latter.

Since participants are volunteers and can disenroll with relative ease, as well as the fact that financial savings can only be realised over time, the programme has an incentive to continue providing a high quality service package to keep enrollees as members. By involving clients directly in the team's decision-making they are likely to increase consumer satisfaction.

The programme helps to improve health outcomes by switching the focus to preventive services that reduce unnecessary institutional and hospital care. Coordinating care helps to prevent the secondary illnesses caused by unrecognised complexity in a client's condition.

Increasing participants' involvement in care planning and service delivery enables people to be educated in the development of their own care plan, ie their care choices in the context of a managed care system, as well as with regards to health

education more broadly.

### Program financing

The programme started in January 1996 as a Medicaid Pre-paid Health Plan with a major grant by the Robert Wood Johnson Foundation. Since the sites are undertaking a lot of preventive health work and therefore saving Federal Medicare payments, the Wisconsin DHFS is aiming to get approval from the Federal Health Care Financing Administration to get a dual Medicare and Medicaid waiver so as to include all acute health care in the capitation fee.

In the programme, community-based organisations enter into a Medicaid managed care contract with the DHFS to implement the programme and receive a monthly capitation payment from the state for each member. Most acute health care services, which account for the bulk of spending, and long-term care are paid out of the capitation payment. Contractors subcontract with hospitals, clinics, HMOs and other providers to ensure a comprehensive network of acute and long-term care. They are responsible for the care of each person regardless of provider or service setting, eg home, hospital or nursing home. Clients are means-tested, but receive free services if they are eligible for Medicaid services.

### Implementation and service delivery

Four sites were up and running in 1999 in Wisconsin, currently providing services for around 430 elderly and disabled people. Sites providing services for the elderly include Elder Care of Dane County, which is a community-based, not-for-profit organisation providing services to the elderly in the county and a full-risk comprehensive PACE site - Community Care for the Elderly in Milwaukee.

The community-based organisations involved in the programme are seeking to collaborate on common functions, eg risk management where they are pooling their resources to provide stop-loss protection. A lot of effort is going into documentation in order to prevent malpractice. Common management information and claims processing systems, as well as clinical protocols, are also being developed.

In a survey conducted in Wisconsin in the mid/late 1980s, 85% of those over 40 years of age sampled in a telephone survey stated that they wanted to remain at home even if they were too frail to do household tasks or prepare meals. Nearly 50% still wanted to remain at home even if they could not carry out the basic tasks of bathing and feeding themselves. Nevertheless, the design of Federal programmes and the accompanying financial incentives mean that, despite this preference to remain at home and a philosophy of independence in Wisconsin, the state still spent \$9 on institutional care for the elderly for every one dollar spent on home and community care services.

### **Example 3: Minnesota Senior Health Options (MSHO)**

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This long-term care programme is unusual in that it is a programme run at the state rather than at the local (county) HMO or private levels. The Minnesota Department of Human Services (DHS) has developed a Minnesota Senior Health Options (MSHO) programme which combines acute and long-term care delivery systems. Like its sister programme in Wisconsin across the state border, it combines Medicare and Medicaid funding. Most MSHO enrollees are low income, frail elderly individuals.

The demonstration programme - like the Wisconsin Partnership Program - is funded by a \$1.2 million grant from the Robert Wood Johnson (RWJ) Foundation to be used over 6 years. The grant is matched by state and federal Medicaid administration funds. In 1997, the RWJ Foundation announced a new initiative to provide \$8 million in grants to up to 10 states to build on Minnesota's model.

#### History

Minnesota was the first state to require enrollment of citizens who were eligible for both Medicare and Medicaid into a Medicaid Managed care programme in 1985. Enrollment of seniors in Medicaid managed care has gone remarkably well with high levels of client satisfaction and few complaints. The elderly are required to choose providers with the Medicaid plan network, but may go out of the network if they pay the Medicare co-insurance and deductibles.

#### Features of the program

The innovative program facilitates the integration of primary, acute and long-term care services for people over age 65, who are dually eligible for both Medicaid and Medicare, and live in the seven county metropolitan area of Minneapolis-St Paul in Minnesota. In order to put this demonstration project into practice, the state has received federal Medicare section 222 and Medicaid section 115 HCFA waivers.

Under the terms of the waiver granted by HCFA, the state is responsible for choosing contractors capable of providing a full range of integrated primary, acute and long-term care services on a capitated risk basis. Minnesota is the first state in the USA to be granted these waivers, which allow it to combine the purchase of both Medicare and Medicaid services into one state-managed contract.

## The client group

MSHO began (voluntary) enrollment in March 1997 and had around 2,500 enrollees in late 1997. MSHO membership is projected to peak at around 4,000 members. This is substantially bigger than many PACE projects and compares pretty favourably, given the short time of enrollment, with the 17,500 enrolled in the Medicaid Managed Care Plans. Nevertheless, it only represents 13% of the potential caseload (18,000) in the metropolitan area that MSHO operates in and 5% of the potential number of 49,000 dual eligible people in the State. 85% of enrollees reside in nursing homes or are nursing home certifiable.

## Goals of the programme

The MSHO demonstration provides Minnesota with an opportunity to more closely align the requirements and payment incentives within the Medicare and Medicaid programmes to produce more efficient service delivery and better clinical outcomes for people eligible for both programmes. The programme aims to meet the following goals:

reorganising service delivery systems to support sound clinical incentives, reduce administrative complexity and create a seamless point of access for all services for clients and providers;

control overall cost growth by providing incentives for lowest cost and most appropriate care, changing utilisation patterns and reducing cost shifting between Medicare and Medicaid;

create a single point of accountability for tracking costs and care outcomes.

## Implementation and programme design

MSHO contracts with 3 health plans to provide all Medicare and Medicaid services, including home- and community-based services and 180 days of nursing home care. Most of the health plans, in turn, subcontract with integrated care systems to provide and coordinate a full set of services. Services include traditional Medicaid managed care services, such as Medicare co-payments and deductibles, medical supplies and equipment, dental care, therapies, prescription drugs, medical transport and home care services as well as hospitalisation and doctor's visits.

In addition, health plans provide extended home care services to frail elderly eligible for nursing home care. Nursing home stays longer than 180 days are paid on a fee-for-service basis. A unique feature of MSHO is that it requires the health plan to be responsible for the first 180 days of care in a nursing home for those who enroll in MSHO while residing in the community.

The programme improves health care for the elderly by providing:

a single coordinated programme which covers both acute and long-term care;  
a single enrollment process for Medicare and Medicaid;  
continuity of care, with a health care coordinator who oversees and guides the

enrollee's care;  
little, if any, paperwork for the enrollee and less administrative complexity;  
better opportunities for enrollees to receive home and community services,  
allowing them to avoid nursing home placement for as long as possible;  
access to specialised geriatric services, provided by care givers experienced  
in the unique medical needs of older patients;  
a single set of oversight, grievance and complaint procedures.

The 3 health plans and their provider partners have put much energy into getting the programme up and running - working hard at enrolling members and marketing the programme. Health plans participating in MSHO have been encouraged to develop new partnerships with primary, acute and long-term care providers and counties in order to serve older people better as well as coordinating care across settings and over time. Plans must provide access to a care manager to each enrollee and involve the client and family in care planning and treatment decisions.

The Minnesota Department of Health has subcontracted an organisation with a good reputation in the field, the National Chronic Care Consortium (NCCC), to provide a technical and educational programme. This programme will provide expert resources (ie concepts and tools as well as clinical expertise) to enable the networks involved in MSHO to integrate acute and long-term care services. The aim is to promote ongoing collaboration about models of best practice and to provide a focal point for working on key issues in clinical care.

The NCCC is a lobby organisation based in the Twin Cities of Minneapolis and St Paul. It counts among its members sophisticated provider systems (hospitals, clinics, HMOs and long-term care providers) throughout the country who are interested in better management of chronic care conditions. NCCC (useful website at [www.nccc.resourcecenter.org/](http://www.nccc.resourcecenter.org/)) is widely known for its work in developing clinical integration tools, such as assessment instruments and protocols, and for compiling information from all over the USA on the integration of acute and long-term care.

#### Difficulties with the MSHO Program

A focus group exercise when the programme had been up and running a while found a number of difficult areas, where ongoing work is required:

integrating providers of care, especially physicians, is proving difficult. Better methods and types of communication are needed to ensure physician involvement and continuity of care;

marketing the options programme is hard. It is difficult to explain to elderly people how MSHO differs from other programmes, eg Medicaid managed care, and there may be few additional benefits for those who already have dual Medicare and Medicaid coverage;

there is a learning curve for providers especially in providing services for community-based enrollees;

breaking out of the traditional processes and procedures adopted by Medicare

and Medicaid was difficult.



## **Example 4: Center for Healthy Aging. California**

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The Center for Healthy Aging is co-located with WISE Senior Services, which offers supportive services to give older adults the option of staying in their homes and communities. The Center integrates care delivery and prevention services. For example, in 1998 it was in discussion with a large local hospital - St Johns - on better management of Medicare services for the over 65s. The hospital was rather inflexible on how services were provided and the CHA felt it could fill in some gaps.

The Chief Executive had a few key messages:

the key to improving outcomes and doing successful promotion work was the ability to collect and track data on individuals. Pooled data sets were vital;

health promotion must start from the basis of 'what does it take to be well'? Elders need a range of services, including housing, health, legal, financial and social support. Multiple entry points into systems of support were important;

overmedication and hoarding of medications by older people was a problem. Retired nurses were an excellent source of expertise who could be tapped by community organisation to help people manage their medications.

### Aims and objectives

The Center for Healthy Aging (CHA) is an outstanding example of an organisation of its type in the field. CHA is a non-profit agency that provides and promotes progressive health and human service programmes to enhance healthy aging. It was established in 1976 and serves a wide range of clients, mainly in the Santa Monica and West Los Angeles area. Its mission is to help older adults and their caregivers meet the challenges that come with aging. Most services are available in Spanish.

### Resources and clientele

The clientele served ranges from those who are healthy and active to those who are most in need of help - including homebound, frail, isolated and persistently mentally ill older adults. CHA has a team of professional staff and over 200 volunteers. It has a turnover of around \$2 million per annum and is funded by a variety of public and private sponsors. Around 30% of its income comes from various Los Angeles

government agencies (mainly for breast/cervical screening); 60% comes from endowment funds, private foundations and individual grants, and the rest comes from fees and training revenue and special events.

### Services provided

CHA provides the following array of health promotion activities and services:

#### *Health promotion activities*

health promotion and prevention services which integrate the physical, mental and social needs of older adults through a range of health care activities; educational workshops and in-home services that teach self-care skills; emotional support through a comprehensive programme that trains older adults to counsel their peers; consultation for older adults and their families/care givers about aging issues.

#### *Service delivery*

assessments of physical illness and assistance with managing chronic illness; high quality services using professionals and trained/supervised volunteers; professional mental health services, including a day rehab programme for chronically mentally ill older adults; co-ordination of in-home services for the frail elderly.

The Center saw its role as providing three main types of services:

providing access to information and services. CHA have one phone number which provides access to services (assessment and planning);

planning aging and preventive services. The starting point is a recognition of the set of risks faced by older people and arranging a variety of services to help people deal with those risks;

providing community support. 80% of care for older people is provided by the informal sector - friends, family, church organisations, etc. CHA aim to build capacity and help the community to help itself by educating systems, such as home health and alcohol services, and to tie services closer together.

### Eligibility and fees

Low income, uninsured, middle-aged and older adults who have no other access to medical care are eligible for breast and cervical cancer screening and physician services. Health education and support groups are open to the community. Services are provided at no charge or on a sliding scale according to ability to pay. Medical or Medicare payments are accepted.

## **Example 5: The Foundation for Accountability (FACCT). Oregon**

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### Composition of the organisation

The Foundation for Accountability (FACCT) is a not-for-profit organisation whose aim is to help individuals make better health care decisions. It was founded in 1995 by a coalition of public agencies, including the Federal Health Benefit Program, the Health Care Financing Administration (HCFA), the Medicaid Program for Massachusetts, the Veteran's Administration, private corporations - eg AT&T, GM - and patient groups, including the National Alliance for the Mentally Ill and AARP. FACCT's Board of Trustees is made up of consumer organisations representing corporate health care, and government purchasers representing 80 million Americans.

### Aims and objectives

FACCT is a fairly new organisation that plays a role somewhere between the King's Fund and the Audit Commission in the UK (with much fewer resources). Its relevance to this report is its interest in providing better information to consumers and improving the incentives for better purchasing of health care for all sections of the population - including older people.

The impetus behind the launch of FACCT in 1995 was the twin beliefs that American health care was under-performing in quality and that informed, motivated consumers are critical to the operation of the American health-care system. One FACCT founder - General Electric Corporation - found that deaths due to medication error and misadventure in the US are 2,500 higher than the failure rates they deem tolerable in the products they (GE) market. This fact was coupled with the realisation that, while there are people who have responsibility for quality assurance, there is insufficient focus within the Health Care Financing Administration (HCFA) on rooting out poor, inefficient or expensive care.

FACCT's goal is to create a common structure and language for quality comparisons. FACCT believes that people need an organising framework to sort and understand complex information about health care performance. The organisation's objective is to enable consumers to write their own contract for care, or at least determine the type of care that they receive.

The aim is that specified performance standards will generate care contracts which in turn will generate good outcome measures. They take as their starting point the view that better information, within a market system, can enable consumers to:

- make better value-based purchasing decisions about plans and providers;
- begin to manage their own health;
- start to guide the health care system.

Their publicity material states that FACCT has five focuses:

- supporting quality-based decisions;
- developing consumer-focused quality measures;
- supporting public education about health care quality;
- supporting efforts to collect quality data;
- monitoring health policy.

As a result of these focuses, FACCT has set up a 'consumer information framework' which brings together a set of measurement sets that apply to a variety of care settings and approaches to financing and organising care. FACCT is still in its infancy and is being expanded and refined continuously. They are aware that to create such a framework, they need to achieve consensus around a standard framework; ensure that it meets the needs of corporate and individual audiences and provide practical help for consumers in making quality of care comparisons.

### The Consumer Information Framework

FACCT built the framework as a tool for Medicare beneficiaries in a project funded by HCFA. It was introduced in September 1997 and is designed to create easy-to-use information resources that help consumers understand health care quality, compare the performance of health plans/providers and make better decisions. It has three components: messages, a model and a set of measures. The messages include:

- "Quality matters - it varied dramatically and is often too low"
- "You have the right to high quality health care and the responsibility to seek it"
- "Quality *can* be measured accurately and fairly"
- "Knowing about quality makes a difference - in your choices and in your care"

The Framework's model organises comparative information about quality performance into five categories based on how consumers think about their care:

**The Basics:** delivering the basics of good care - access, skill, coordination of care, communication and follow up;

**Staying Healthy:** helping people avoid illness and maintain health through education, prevention and risk reduction;

**Getting Better:** Helping people recover when they're sick or injured with appropriate treatment and follow-up;

**Living with Illness:** Helping people with chronic conditions reduce symptoms, avoid complications and maintain daily activities;

**Changing Needs:** Caring for people and their families at the end of life or when functional abilities change dramatically.

Concerning measures, FACCT has designed an eight-step process for scaling, standardising, weighting and combining quality measures to create composite scores for the model's categories and subcategories. Various sources have been used - of which the most important are the National Committee for Quality Assurance's HEDIS and the Agency for Health Care Policy and Research's (CAHPS). These systems, however, only provided measures for two categories 'The Basics' and 'Staying Healthy', so FACCT undertook research and development to develop measures for the other categories.

Measurement sets now exist for adult asthma, breast cancer, diabetes, major depressive disorder, health status (over 65 and under 65) and health risks. Measures are under development for alcohol misuse and dependency, children's health, coronary artery disease, end of life and HIV/AIDS.

To develop measures, FACCT conducts focus groups and other research to understand the aspects of quality that are important to consumers. The FACCT framework commendably reflects an emphasis on outcomes focused and patient-focused measures, whatever their source.



# **THE BOUNDARIES BETWEEN HEALTH AND SOCIAL CARE FOR OLDER PEOPLE IN DEVELOPING COUNTRIES**

## **III. COUNTRY CHAPTERS**

### **B. NEW ZEALAND**

#### **B1.1 Summary and Overview**

**New Zealand's health care system and other public services have been subjected to a great deal of change** since the Second World War and this tendency has accelerated in recent years. This restructuring of health services has displaced some competent people, generated an environment of self-preservation and has had a negative impact on service delivery and morale. Most policymakers and service providers now want a moratorium on further organisational changes.

With a relatively small population of 3.7 million - roughly equivalent to a large English conurbation outside London - **policy change has been relatively easy with a 'can-do' culture** and fewer forces standing in the way of change.

However, the flip side is that there has been a history of fragmented policymaking and changes being made without being piloted, without a firm evidence base and with little, or no, systematic follow up. Partly for these reasons, the **New Zealand health system is one of the most unpopular in the OECD area.**

In the field of disability and long-term care, there is a fairly widespread view (shared by agencies such as Age Concern) that the **policy has been characterised by a lack of effective planning and policy direction** and sham consultation which, in turn, has prevented the delivery of comprehensive and integrated health care.

They point to problems including **limited provision of home support services, lengthening waiting lists and the increased fragmentation of services** due to services being contracted out. These are seen as evidence that the current system is not delivering adequate care ("Core Issues in Health Care Services for Older People", September 1997).

#### **Organisation and funding**

In New Zealand, **the Health Funding Authority (HFA) funds both mainstream health services and social services**, which in theory allows the HFA to coordinate services across the social/health services boundary.

However, the division of purchasing responsibility within the HFA means that **organisational boundaries still exist between personal health, disability services and mental health**. Integrated care is also made more difficult by the fact that acute and community hospital services also operate autonomously.

### Strengths and weaknesses

The strengths of the New Zealand system are:

a **clear strategic framework now exists** for both health policy and specifically for mental health;

due to its particular history of conflict and integration, **the rights of ethnic minorities are taken seriously** and not simply paid lip service to;

an orientation - and practice - which **takes the involvement of the family seriously**.

The weaknesses include:

in the past (and possibly in the future), **overly rapid changes in government structures and policies**;

a **lack of inter-agency cooperation and collaboration** - in particular, poor cooperation between primary and secondary providers resulting in a struggle by different parts of the system to retain control, and inadequate sharing of information;

an **underdeveloped model of public health and over-concentration on medical and residential models** of care;

in mental health services, there is a **clear shortage of staffed supported mental health accommodation in the community**;

**New Zealand has one of the highest suicide and depression rates among adolescents and young people**. Despite this fact, mental health services for children and young people are inadequately funded.

### Lessons for other countries

New Zealand has been described as 'policy wonk' heaven, with a small geographically concentrated policy community, a small population base and rapid evolution of governments and policies. New Zealand **pioneered the purchaser-provider split and has provided the test-bed for many new and original ideas**. Examples of **schemes and policies which are at the international cutting-edge** include geriatric care schemes such as 'Elder Care Canterbury', the 'Strengthening Families' initiative and the involvement of the extended family in treatment as well as a highly cultural awareness and understanding of ethnic minority communities.



## B1.2 The Strategic Framework

New Zealand is a small country, economically dependent on foreign trade, with a somewhat unstable unicameral system of government. New Zealand has a relatively 'young' society with around 10% of the population aged over 65, compared to, for example, Sweden with 22% of the population over 65.

Health policy - including long-term care - is set by the Minister of Health advised by the Ministry of Health, which is responsible for negotiating, managing and monitoring funding arrangements with the Health Funding Authority (HFA).

The Ministry of Health provides policy advice on all health and disability issues, including regulation, allocation, financing, service delivery and oversight of the system, while the HFA acts as the health purchaser and allocates resources. HFA officials, perhaps naturally, saw their organisation as having the upper hand in funding negotiations with the Ministry. Evidence for this is that the HFA draws up the funding agreement and then passes it to the Health Minister for approval.

There has been very little top level planning in the past - priorities have not been clearly and consistently set between the various sectors. This has resulted in what one senior Ministry official described as "chaotic services" and "poorly targeted expenditure". There is still a strong tension (and New Zealand is far from unique here) between medically-driven services operating out of acute hospitals and community-based initiatives.

Partly no doubt to address the criticisms of ad hoc policy making in the past, a clearer (though still moveable and moving!) architecture and strategic policy framework has been drawn up for health policy and specifically for mental health. Ministry officials stated that they had three overall aims:

- setting a coherent medium-term strategy;
- securing labour flexibility, which they saw as breaking down into delegation and competence issues;
- delivering integrated care.

The objectives underpinning these concerns were:

*to encourage devolution*, so that local people could take local decisions.  
Purchasing was being devolved to Hospital and Health Services (HHSs) via the HFA, and nurse delegation was being explored;

to explore *new types of service delivery* and pilot schemes which might deliver more integrated care.

The new integrated Health Funding Authority is overall probably an improvement on the previous four separate authorities, which required nationwide service providers to have four different contracts and to contend with different standards and bureaucratic arrangements in each area. A single HFA also means that a single

organisation is responsible for providing advice on policies, funding and the cost of new programmes.

### Health promotion

New Zealand is concentrating on preventive health care, improving health visiting and supporting needy families. Age Concern told me, however, that older people have trouble accessing early intervention and rehabilitation services.

Population health initiatives have tended to be highly targeted and focus on the poor working-class population. This policy has had several strands:

'wellness clinics' run by GPs;

public health services (immunisations, etc);

population-based strategies, delivered mainly through personal health services;

policy measures which use the results of international work on the determinants of health.

The National Health Committee's report on the social, cultural and economic determinants of health provided strong evidence to show that factors other than health care strongly affected health. This finding highlighted the need for the Government to find a new approach to address the health problems of those in the lowest social classes. The result was the 'Strengthening Families' Initiative (see Positive examples of cross-boundary working in Section B1.5 below).

### Long-term care policy

The Government commissioned a report on long-term care (*Care for Older People*, Richmond et al) which was published in 1995. However, the issues that it raised were not acted upon and, instead, further work was devolved to a Taskforce on Healthy Aging. There is some feeling among geriatricians in New Zealand that care issues affecting older people have been neglected.

The Prime Minister's office believe that the aim of current social policy is to make it easier for consumers to access services. Key influences on policy have been the rise of feminism as a political force and the consumer rights movement especially among people with disabilities. More flexibility and openness in arrangements is seen to be crucial.

There is a debate about whether a common framework is required for ongoing support services for older people, the learning disabled and people with mental health problems. One outcome of this debate is a growing consensus that a one-size-fits-all framework does not work.

## **B1.3 Roles and Responsibilities of Different Agencies**

### **1.3.1 The Health Funding Authority**

The funding and commissioning role has been made the responsibility of a single agency - and key player is the New Zealand system - the Health Funding Authority. The history is that Hospital Boards gave way to Area Health Boards in the 1980s, followed by the introduction of the purchaser/provider split in 1990 and the creation of four Regional Health Authorities (RHAs) in 1993.

Following the election of a new coalition government in 1997, a Transitional Health Authority replaced the four RHAs in July 1997, who were effectively merged into a single Health Funding Authority (HFA), separate from the Ministry of Health. Ironically, if a new Labour-led government were to be elected in 1999/2000, it is possible that the HFA will be reabsorbed into the Ministry of Health.

The HFAs functions and objectives are set out in the 1993 Health and Disability Services Act and the 1995 Amending Act. Its role includes: assessing and monitoring health and disability support needs; funding health and disability support services and balancing the demands for services within the budget available; monitoring the performance of contracted providers and pushing for progress on the Government's priority areas such as mental health and Maori health.

The HFA is functionally organised in five directorates - personal health, disability support services, mental health, public health and Maori health. Within each of these directorates, there are teams responsible for framework development, locality management and change management. The key to this framework is the arms-length operation of the HFA.

A key feature of the current New Zealand system is that the funding for both personal health care and disability support services (DSS) has been brought together through the HFA and funded from the health vote.

Within the HFA, responsibility for commissioning is devolved on a locality basis mirroring the old RHA structure. Each locality manager negotiates a contract for a quarter of the New Zealand population (ie under 1 million each), with a budget of approximately NZ\$850 million. Their role is that of a traditional purchaser, ie to set the budget, minimum service requirements and attempt to buy the best services for the money available.

At first sight, this would seem to allow the HFA to coordinate services across the social/health services boundary, prevent cost-shifting and make efficient purchasing decisions. However, the current system has two weaknesses:

given the split of purchasing responsibility within the HFA, organisational boundaries still exist. Although primary and secondary care have been integrated within the HFA's Personal Health directorate, this has created boundaries between personal health, disability services and mental health;

the HFA, rather like the old Regional Health Authorities in the UK, appears to

be too subject to influence from politicians.

### **1.3.2 Independent Practitioner Associations**

In New Zealand, GPs are self-employed professionals who employ practice staff directly. Many of the country's GPs have banded together into Independent Practitioner Associations (IPAs), who negotiate with the HFA for funding. Most are still paid according to fee-for-service arrangements, which it was recognised provides an incentive to over-service. Some IPAs who treat a mainly low income population are paid on a capitation funding basis.

IPAs vary in the quality of their members. The Pegasus Group, which includes most of the GPs in the Christchurch area is recognised to be one of the most progressive IPAs.

### **1.3.3 Voluntary and Maori organisations**

Voluntary organisations are very important in service delivery in New Zealand. Some of the most prominent are: Plunkett (a Health Visiting organisation), IHC (a big Disability Services provider) and CCS (an umbrella organisation for the disabled). I spoke to directors of both the IHC and CCS. Church providers - Presbyterian, Baptist and Methodist - are also very important in the provision of services for older people.

The Maori community has, in general, worse health than non-Maoris and faces problems in accessing health services, including for long-term, chronic and palliative services. The Iwi - Maori tribal organisations - contract separately with health and social services agencies (especially with regard to children and justice issues) to provide services. They are keen to tackle Maori health problems, which they see as arising mainly from social circumstances.

## **B1.4 Financing Arrangements and Accountability Mechanisms**

The HFA is responsible for providing the best mix of services across the population. I was told that the HFA is trying to reduce costs and budget allocations to those over 65 compared to younger adults.

With the exception of mental health, which is ring-fenced, and funding for aids and adaptations, which is purchased on behalf of the DSW by the Community Funding Agency, all services are funded from the health vote. 50% of the health vote goes to private providers (GPs, laboratories and drug costs). The proportion of funds from the health vote (roughly NZ\$6 billion) going into the various health services is:

<u>Service</u>	<u>Percentage</u>
Personal Health (primary & secondary care)	73
Public health (health promotion)	2
Disability Support Services	25
TOTAL	100

Although it accounts for under a quarter of the health vote, the Disability Support Services budget funds around two-thirds of service provision for people over 65 years of age. However, in New Zealand (unlike in the UK, apart from the very recent 'Partnership' arrangements) the Personal Health arm of the HFA can transfer funds to the part of the HFA that funds Disability Support Services.

The HFA would like to be able to merge their funding into one 'bucket', but the Treasury is opposed to this due to concerns that there are insufficient checks in the system to control budget 'blowouts' and that too much money would be spent on acute care services at the expense of spending on community and disability services.

Lobby groups have acknowledged the work that the HFA has undertaken to derive more consistent contract specifications, service delivery mechanisms and pricing methodologies. This task includes drawing up accepted adjustments for quality differences and developing risk-sharing contracts. Ministry of Health officials observe that the HFA is reluctant to bear risk itself and is keen to develop capitated contracts which pass the risk of cost increases on to providers.

In early 1998, the HFA had three performance measures which were relevant for health services for older people. These were;

- to improve the coordination and integration of disability support and ensure needs assessment facilitation coordination services are available in all regions;

- to ensure that access to services reflects the greatest need, the HFA will have in place consistent processes for prioritising need;

- to ensure quality residential services,... all residential services will be subject to audit.

However, and disappointingly for an organisation born from a radical purchaser-provider split in health care and working with a reasonably clean slate, the HFA has not yet moved beyond output-based funding to outcomes. Valid issues which need to be addressed include: the measurement of outcomes; the appropriate time frame to look at outcomes (annual contracts or longer/shorter periods); how to separate out the individual contribution of different services.

There are 28,000 nursing home beds in New Zealand, many of which are run by church-based organisations (eg the Ecumenical Care Group). Roughly half the places are publicly subsidised, with funding administered centrally by the Health Ministry, and half are privately funded. This is a substantially larger private funding share than in the UK.

Prior to 1993, the funding of residential care was funded by the Department of Social Welfare, and nursing homes were funded by the Ministry of Health. It was decided in 1993/94, after public consultation, to place disability policy and the associated funding for care of older and disabled people under the Ministry of Health rather than

under the Department of Social Welfare or under a separate agency.

Long-term care in nursing homes is now subsidised by the HFA but is income- and asset-tested. The ceiling before assets are taken into account is NZ\$50,000 for a couple with a spouse living at home (excluding the home) and around NZ\$30,000 for single people, with the home taken into account.

Home-based care, as in the UK, is more expensive for the public sector. A holder of a Community Services Card can get home-help - and respite care - without paying fees and everyone can get attendant care (for bathing and dressing) free.

### Accountability

Accountability is seen to be an important issue by policymakers, the Treasury and providers. The Treasury argued that there are two separate ways the HFA ought to be accountable: first, for delivering outcomes and, second, in purchasing the services they are contracted to purchase.

In practice, however, there does not exist enough information does not exist to determine the best mix of services. This means that better arrangements linking dollars to services are needed, covering issues such as access times and the location of services.

New Zealand has gone quite heavily down the contracting route for the provision of services. Voluntary organisations (eg CCS) told me that they found contracting was giving organisations too little scope to deliver services the way they saw fit and challenged their values.

A better model was felt to be 'relationship contracting', where outcomes were agreed and the need to maintain an ongoing relationship was acknowledged. CCS felt that it was best to devolve service delivery and accountability to localities (eg GP practice areas or social services department local area offices), rather than try to impose policies from above.

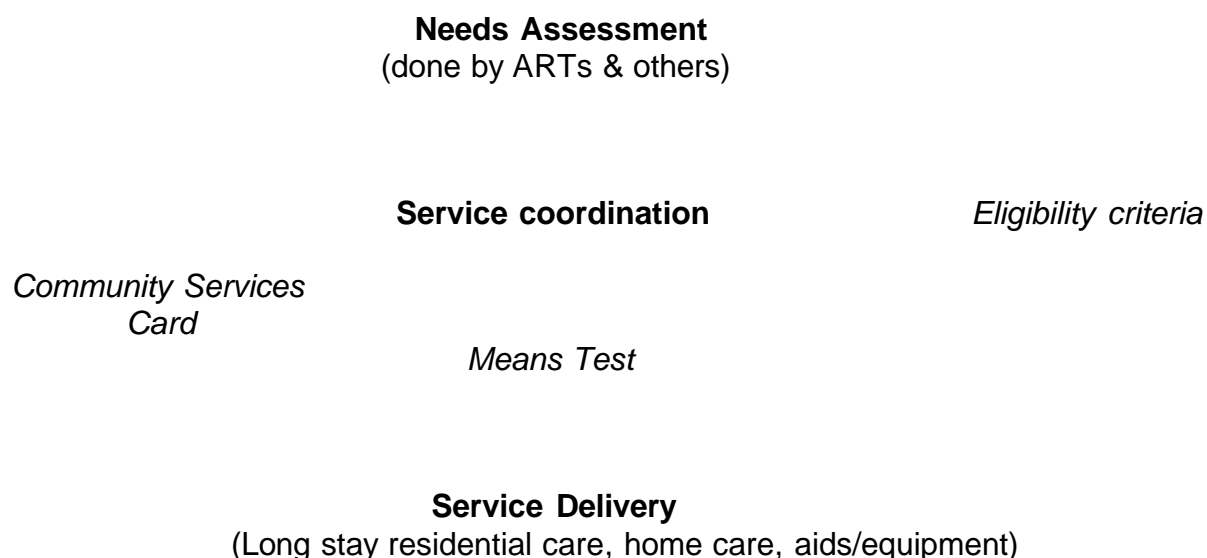
## **B1.5 Service Delivery Arrangements**

There is a fairly rigid purchaser-provider split in New Zealand and a separation of the needs assessment and service coordination function. The HFA purchases assessment services from hospital-based Assessment, Rehabilitation and Treatment (ART) teams as well as from other agencies.

In social care, there has been a strong tradition of state provision of social services. As in the UK, there has been a history of direct provision of long-stay geriatric beds, pensioner housing - backed up by a largely private rest home industry. In the late 1980s and early 1990s fuelled by economic crisis, there was a retrenchment of state-funded activities.

The Government also became frustrated with a lack of planning and cost shifting and brought disability policy together in the Ministry of Health (although older people objected initially to being 'lumped in' with disabled people). This has the advantage that all services for older people - from acute hospitals, through personal care to disability support services - are provided by a single ministry. It should also generate a greater policy coherence and an ability to plan services better.

A representative view of the service model is as follows:



There is still a tension between Hospital and Health Services, ie services delivered out of hospitals and community initiatives.

Before the reforms, home care services (home helps, district nursing, bathing and other personal care) were provided by hospitals. Older people could also employ their own help with assistance from public funds. Now agencies, such as Nurse Maud (Christchurch), church agencies and commercial companies, provide home help. Home care budgets, however, are still overspent with excess demand for care - especially 24-hour or round-the-clock care.

There is also the danger that contracted services and/or services provided by specialist agencies may mitigate against a holistic model of service provision.

## **B1.6 Broad Policy Debates**

At the end of 1997, Age Concern New Zealand wrote:

"Health care provision for older people is clearly deteriorating in the present climate of restrained government spending and the market-driven ethos dominating health care purchasing decisions. The negative impact of these policies on health services for older people is unacceptable." *{Core Issues in Health care Services for Older People, Age Concern NZ, September 1997.}*

They identified six major areas of concern:

- a lack of policy direction and planning;
- an inadequate allocation of resources;
- excessive regional variations in services;
- increased fragmentation of services;
- reduced quality and limited provision of home support services;
- lengthening waiting lists.

Subsequently, a number of lobby groups (the Older People's Health Forum) met the Minister of Health and called for: the development of long-term strategy measures against key health outcomes for older people; more detailed performance and accountability measures for decision making and purchasing; nationally agreed standards for service delivery in all settings; adequate resourcing; a flexible, consumer- focused approach to contracting and service delivery.

### **1.6.1 Boundary issues**

As in other countries, New Zealand has a policy of aging in place and progressively moving people through more intensive forms of care. However, there has been little congruence between health and housing policy. The key problematic boundary is that between primary and secondary care. Doctors are often not involved in assessment. Integrated health care is also made more difficult by the fact that acute and community hospital services operate autonomously.

New Zealand has gone for transparency and 'vertical' policy coordination (by the Ministry of Health). However, some groups - probably the more disadvantaged require horizontal policy integration, where all services are purchased by a case manager. There is, thus, a debate about whose responsibility it is to assist providers to improve the management of health care - hitherto the HFA has not really seen this as its job - but if it is not the HFAs job, it is not clear whose job it is.

Someone with needs that go beyond the health sector, for example a physically disabled person, might easily have a total of five or six separate contacts within the HFA-funded health care system. These could include the following services: in-patient care; residential care; home help services; pharmacy; GP services; the Accident Compensation Scheme (ACC) and income support supplements.

There are over-rigid boundaries between Personal Health and DSS services, which do not seem to recognise the interplay between services for older people and claims



for disability benefits (eg sickness and invalidity benefits). Effectively, Disability Allowance acts as a safety net.

To address the need for 'joined-up' working, the HFA has been looking at:

- how to get a set of consistent purchasing principles and practices;

- how to respond to boundary problems and changing technologies;

- how to get a view over the whole episode of care instead of a series of provider interventions.

A key issue is what the HFA ought to be doing to draw together personal health services, disability support services and mental health services. In practice, boundary problems are addressed through devising protocols, eg through teams set up between the HFA and the ACC and through ad-hoc funding provision.

The most pressing boundary issues in primary care include the interfaces between GPs and Community Health services (district nursing, physiotherapists and specialist nursing), where there are problems in chronic care, eg for asthma and the boundary with hospital services. It is rare that a GP will be knowledgeable enough to treat disabled people successfully and develop a community-based service, but it is clear that medical practitioners need to be involved.

Other issues arise at the interface between health and disability services. These include: user charges and affordability concerns; policy on the Community Service Card; the use of long-stay and residential care; home management services; the availability of aids and adaptations. In the past, most social services for older people at home and the disabled used to be demand-driven and delivered through the Department for Social Welfare. These services have since been imported into the Ministry of Health.

The ingredients of integrated long-term care are thought to be:

- systematic multidisciplinary screening and needs assessment;

- appropriate attention to housing and transport;

- accessible services;

- constant contact with the family, with cases reviewed and the resulting information shared with family members.

A New Zealand home care study showed that with the right group of people, ie those eligible for residential care, the total cost of care can be 30% less at home compared to institutional or hospital care. The report also shows that there are savings if people can be kept out of nursing homes. Home care policies showed that 20% of people receiving targeted care stayed at home for over 3 years.

### Positive examples of cross-boundary working

An interesting example of cross-boundary working in a related area to long-term care is **the 'Strengthening Families' initiative**. This has been driven by the Chief Executives of Health, Social Welfare and Education, directly accountable to Ministers and then 'sold' to people working in downstream agencies. Memoranda of Understanding were agreed by social, community, voluntary and government agencies, which have now received government backing. Merged funding streams were signalled in 1991, legislated for in 1993 and implemented in 1996.

The initiative recognised that 50% of all families/individuals are not at risk, a further 45% are at risk and 5% are deprived and have multiple needs. Previously, these families received multiple visits from agencies, with an average of 4 separate agencies being involved. One family received a record of visits from 17 different state and private agencies. This was recognised to be unnecessarily intrusive, duplicative and inefficient. See Best Practice Section below for more details.

Another good example, again not in long-term care but in another social care field, are **youth offending teams**. These have been at the cutting-edge of involving families and have aimed to solve problems by first working at an interpersonal and community level (eg by securing apologies and remedying grievances).

## B1.7 Best Practice Examples

### Example 1: Elder Care Canterbury. Christchurch

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*"Effective provision of health care for older people is a major challenge for the New Zealand health system. Most structures and systems in acute hospitals in New Zealand, and elsewhere in the developed world, operate with the unstated assumption that each health care intervention is discrete and measurable ... Consequently acute hospitals may provide a technically excellent health intervention to a frail elderly person, but find that it is ineffective due to previously unrecognised pathology, disability, psychological problems and social difficulties."*

(Dr Nigel Millar, *A Model of Aged Care Reform* in A Bloom ed., *Health Sector Reform in Australia and New Zealand*, 1999).

Elder Care Canterbury (ECC), based in Christchurch, New Zealand, is an innovative project which seeks to provide integrated care for the elderly in Christchurch and the surrounding area (Canterbury) - an area of mid-southern New Zealand covering approximately a quarter of New Zealand's geographical area.

ECC has a population catchment of around 400,000 - roughly equivalent to the population of a UK health authority - with 50,000 people aged over 65 and 20,000 aged over 75. The project leaders are not aware of any other service model in the world trying to provide integrated care over as large a range of services and for such large numbers.

The project is not a defined corporate body and has no formal business structure. It depends on a written understanding by the major health and disability service providers for older people in Christchurch. ECC is clinically led and is a partnership between the specialist health service for older people (Healthlink South); the main primary care Independent Practitioner Association in the area, which includes most GPs in Christchurch and represents all the rest (Pegasus Medical Group) and the major acute provider (Canterbury Health).

This project is an excellent example of its sort, although, as many of these pioneering schemes are, it is still in its early days. Some of the impressive features

of this projects are its holistic focus, the use of a coordinator/facilitator who is both independent and has specialist management skills, and the integration of acute and rehabilitative care - due mainly to close working between medical staff, led by geriatricians. The proof of the pudding will be how well this way of organising care copes with increases in the volume and complexity of care.

Although the initiative focuses only on the 'older' elderly (those over 75), it is firmly located in the body of existing services. This contrasts with the limited nature of the PACE projects in the USA, which only work with the most severely sick and handicapped elderly. This type of integrated care model is probably therefore better able to spread risk and cost of treatment, which in turn should help to contain the costs of the rising demand for care.

The budget of the current project is estimated to be about \$300,000 a quarter - mainly costs of project management and administration. Clinical staff costs are met out of existing budgets. In 1998-99, the project was still dependent on a good deal of unpaid voluntary work from clinicians, social and voluntary care providers. However, new funding will need to be found as this 'goodwill' from staff cannot be expected to last indefinitely without proof of the efficacy of the new way of working.

Evaluation and research therefore need to be undertaken to evaluate the effect of this new care delivery model on outcomes, quality of care, waiting and treatment times, and costs per patient. A more 'integrated' model should at least reduce some duplication and, to the extent that care is provided by more appropriate professionals, improve care and reduce costs. But the most demanding test will be to see if it improves outcomes, as opposed to solely improving quality, worthy as that is in its own right. There is still only patchy evidence that integrated care programmes have significantly improved outcomes, as opposed to quality.

### The service model

ECC targets older people who require access to specialist health services - predominantly but not exclusively those over 75 years of age. People over 65 with mental health and organic brain disorders, as well as younger people with health disorders associated with, or complicated by, the aging process are also served within the project.

The ECC's overall 'mission' is for all parties to work cooperatively to develop a seamless and effective health service for older people. Its subsidiary aims are to:

- 1) develop a comprehensive health service for older people in its area;
- 2) work with the community in an inclusive and collaborative way to develop the best possible service;
- 3) focus on the skills, knowledge, enthusiasm and commitment of the existing local providers and the wider community to design a service that meets the specific needs of older people in the Canterbury area.

Early work on the project identified the major challenges facing health services for

older people. These were: the predicted demand on health services (a 35% increase in demand for health services for the over 75s, 60% for the over 80s and 90% for the over 85s - the acute service is already experiencing a 10% increase in acute admissions each year); the costs of provision; the quality of patient care.

### Benefits of the project

The benefits of the project are expected to be threefold:

breaking down of professional and institutional boundaries which tend to stand in the way of service development and better patient care;

improved effectiveness through a reduction of duplication of activity and reducing delays in accessing care which leads to reduced health status and poorer health outcomes;

improved efficiency, by streamlining procedures and providing better care, thereby reducing lengths of stay and giving greater health gain per \$ spent.

The genesis of the new pattern of service delivery was a series of discussions in July to December 1996 between geriatricians and consultants at Healthlink South and Pegasus GPs about integrating services for older people in the Canterbury area. This created tensions, but eventually led to a professional agreement between Pegasus GPs, specialists (geriatricians and old age psychiatrists) and CEOs of the main health providers to integrate services early in 1997, in response to an HFA invitation to tender for an integrated care service for the elderly.

The principles of the partnership, which have allowed it to succeed are:

- 4) a realisation that bringing the existing players together more effectively would be more efficient and less disruptive than setting up a new organisation. The key guiding principle is that the care process should be patient-centred;
- 5) a holistic approach, focusing on the whole service, from education and health promotion through disability support services, assessment and rehabilitation to acute medical and surgical services;
- 6) an inclusive.
- 7) an inclusive open dialogue between clinicians and management in setting up and designing the partnership process and structure;
- 8) a lean management structure, with one project coordinator focused on delivery, using a proven project methodology derived from an example used by the Leicester Royal Infirmary in the UK;
- 9) strong commitment from the outset from senior clinicians and support from CEOs of main health organisations.

The key success factors have been threefold:

- 10) the creation of an environment where the accepted locus of control was no longer certain, but participating stakeholders felt sufficiently confident and committed;
- 11) encouraging the health professionals to lead change internally, through initiatives they generate, rather than having change forced on them;
- 12) its inclusive approach in which criticism is actively sought and constructively answered. Potential conflict is exposed and diffused early, leaving energies to be channeled into improving health care for older people locally.

The project leaders believe that integrated care needs to be done bottom-up as well as involving people with leadership skills. ECC acknowledge a number of stakeholder groups, which have evolved in structure over time: the Community (not-for-profit organisations, local and ethnic/Maori groups); health service providers (as mentioned above); disability service providers (nursing & rest homes, domiciliary care providers, private therapists and voluntary agencies); support service providers (pharmacists, labs and diagnostics); Crown agencies (Treasury, HFA, Ministry of Health, etc).

ECC have so far selected four initial projects out of the large number of potential projects to improve health services for older people. These are three condition-specific projects - stroke, broken hip (fractured neck of femur) and acute confusion - and one generic project on positive aging. A separate team will look at contractual and funding arrangements relating to each project. The guiding light in each project is 'does the new service/information provide a better focus on the person/patient?'

Examples of the issues the projects are wrestling with include the need to write a protocol on how patients with a broken hip are treated post-operation so that rest homes and private hospitals are more diligent in aftercare; improving the primary care/A&E relationship and ensuring adequate surgical cover on particular sites. The aim is to eliminate problems and unnecessary costs resulting from patients being admitted for high technology interventions (eg CAT scans) without first being seen by a specialist physician.

## **Example 2: The 'Strengthening Families' Initiative**

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This initiative is an interesting example of cross-boundary working in an area related to long-term care, bringing together health, housing, education and social welfare departments.

In New Zealand, the traditional view has been a 'welfarist' one - namely that individual failings are ultimately due to failings within society. However, over time there has come a realisation that changes to the lives of problem families have to come from within the family unit, not externally.

Hence, partly inspired by practice in the USA (eg 'Healthy Start' in Hawaii), a view developed that New Zealand needed to develop a programme of intensive family support, including home visits. Families were enrolled in an 'Early Start' programme and allocated a family care worker.

Initially, 50 families were chosen and were stringently supervised. The programme concentrated on teaching families new coping skills, such as going to the doctor and managing depression.

One of the lessons of the programme was that some things were relatively easy, including: immunisation, preventive health checks and medical diagnoses since the latter had clear procedures and mechanics. The difficult parts of the programme were raising the family income and dealing with drug and alcohol abuse. Families with severe difficulties were found to have a constellation of personal failings, a lack of skills and, due to income and other pressures, had very little time to address their underlying needs. The most hopeful answers included taking up part-time employment and allowing individuals to retain benefit income for a period before it was withdrawn. Family Support Workers - often educated women providing wise counsel and support - were also found to be very helpful.

The two central findings were that problem families were 'over-serviced', but with little effect on outcomes, and that changing abusive lifestyles is very hard. It was too easy to get into 'Early Start', and there was insufficient 'buy-in' from the poorest families.

As a result of these lessons, the 'Strengthening Families' initiative was born. The programme's academic sponsors felt very strongly that it was necessary to run the study first on a pilot basis, in order to generate objective evidence of improvements in outcomes. Hence, four pilot projects with different features were carried out in the areas of West Auckland, Whangarei, Christchurch and Rotorua.

Under the programme, a voluntary organisation - Plunkett, who provide peri-natal care - screen high-risk families. If families meet two out of eleven key deprivation criteria, then they are referred to a consortium work team. A needs assessment is performed within one month, and then if further intervention is indicated, they are invited to join the programme. These families are then referred to various providers who can provide home-based family support for up to five years.

The 'Strengthening Families' programme includes the following key components, which are deemed integral to its success:

- local coordination using protocols for case management in local communities. Typically, case conferences are held with all the agencies involved (housing, police and voluntary agencies);

- one care and service contract per family. A targeted home visiting service is given to the 15% of families deemed to be most at risk. This is jointly funded by new money and monies from existing budgets;

- a joint approach, to secure full 'buy-in' from the family, using a 'code of social and family responsibility'. The approach concentrates on improving income bases and employment, with structured activities and goals.



# A STUDY OF THE BOUNDARIES BETWEEN HEALTH AND SOCIAL CARE FOR OLDER PEOPLE IN DEVELOPED COUNTRIES

## III. COUNTRY CHAPTERS

### C. AUSTRALIA

#### C1.1 Summary and Overview

Australia has elements of the US system, eg fiercely independent fee-for-service GPs and an almost entirely privately delivered care system. But Australia also has a European heritage of strong central policy direction, mainly provided by the Commonwealth, with significant funding for primary care and publicly funded acute care for all (see the Annex for a brief description of Australia's health care system and structure).

#### Positives and negatives

There are a number of very positive features about Australian long-term care:

it probably has a **more integrated system** for care of the elderly than many others countries. Many ministries span health and social care;

**an agreed strategy exists** for elderly care;

there is **broad-based screening** for access to care;

the Coordinated Care trials are beginning to yield **interesting models of delivering integrated care** to the chronically ill.

But problems remain:

Australian aged care is characterised by **too many programmes**, each of which has their own approach to rationing and their own waiting-list criteria;

**funding and policy is still largely split** into acute health, primary care and community care 'silos', which frustrates policy integration;

the **tension and confusion of responsibility** between Commonwealth and states is a constant irritant and does create some perverse incentives;

most of Australia (with some clear exceptions) still seems **over-reliant on residential care and over-bedded** compared to international best practice.

## **The funding picture**

As elsewhere, aged care spending, while not in any sense trivial, is pretty small compared with the much larger national Medicare (GP services and public hospital care) and Income Support programmes. Private funding of Australian health and social care is much more significant than in the UK and much of Europe. Even among the elderly (with lower incomes) around 30 per cent of hospital use is in the private sector.

Another clear difference compared to the UK is that patients contribute towards the cost of primary care, although the costs borne by patients are probably not as large as in New Zealand, and some escape entirely through GP bulk-billing arrangements, available to those with a health care card. As in Europe, most social care services are means-tested and, overall, the welfare system is more targeted than in the UK, with half of the aged population charged fees for their care.

## **The care system**

Australia's residential care system, funding and administration is almost entirely driven at a federal level and states' spending is only around 10% of total aged care spending. Most care dollars are spent by the 5 or 6 big agencies (eg community nursing) in each state. Nevertheless, in Australia, like the USA, the states have different systems and emphases - reflecting their history and pressures. States also vary widely in the size of their population, care needs and local governments' capacity to raise income, so few pan-Australian generalisations on care patterns are invariably true.

For example, the two most populous states - Victoria and New South Wales - have different models of care. The Victorian Government has historically had a large social role in the provision of home and community care services (meals on wheels, etc), while NSW has a great diversity of small community agencies providing locally based care. South Australia, with a population of only 1.4 million concentrated around Adelaide, has a reputation for innovative service delivery models (see Aged & Community Housing in Best Practice section).

## **Aged care policy trends**

As a result of a consistent policy direction over 13 years - between 1983 and 1996 - under a series of Labour governments, and an injection of resources, Australia has made some progress in moving away from institutionally-based care models and the unenviable position in the early 1980s of having the highest proportion of elderly people in nursing homes in the OECD. There is now a much clearer 'consumer' orientation, and community-based care has substantially expanded since the mid-1980s, both through traditional home-delivered care services and, more recently through the Commonwealth's Community Aged Care Packages.

Australia has a much more highly regulated system of residential provision for the elderly - mainly through strict supply side controls over the number of nursing home and hostel places - than the UK. On the positive side, the ability of the

Commonwealth to shape the provision and location of residential care facilities through top down benchmarking of provision and a quality monitoring process has helped to push through change in an otherwise pretty bureaucratic system.

The diversion to home-based care was driven initially by tough supply side controls on bed numbers. In the late 1980s, the Treasury froze the numbers of funded beds in residential care (though the cost of each bed increased and spending on residential care continued to grow, despite the decline in the number of beds). Benchmarks for the numbers looked after in different settings were also used to divert people from nursing-home to home-based care. Nevertheless, HACC services still had to rely on new money and, in fact, there was little saving from residential care. It would be interesting to know how much of the real growth in residential care costs was due to higher dependency levels.

Nevertheless, the 'planned' approach to expanding HACC services has been pretty successful, although the numbers on CACPs themselves are still pretty modest (around 4,000). Figures supplied by Anna Howe show that out of the population of about 530,000 over 70 years of age with a moderate to profound handicap, nearly 400,000 (around three-quarters) are living in the community and 140,000 (one-quarter) are in residential care. Approximately 170,000 clients aged over 70 are receiving community care, whether through HACC services, Community Options or CACPs - a coverage rate of the target frail aged population in the community of around 40%. This high level of coverage is accounted for by a large number of clients receiving only fairly basic services such as transport.

Furthermore, a comparison of spending tells a somewhat different story in terms of the balance between residential and community-based care, reflecting the high cost of residential care. Between 1985-86 and 1993-94, the amount spent on home care for the highly dependent elderly over 65 rose from \$15 to \$23 out of every \$100 and will probably rise further to over \$30 by the end of this century (Gibson, AIHW). But the conclusion is that - as elsewhere - the bulk of the public health dollar is still being spent in institutions.

Most of Australia - with some clear exceptions - still seems over-reliant on residential care and hence over-bedded compared to best practice in USA, eg in Wisconsin and Oregon, and in Europe, where diversion has now been pursued energetically for a number of years. But diversion, where it has occurred and has been moderately successful, still begs the question of how care will be paid for.

Although Australia's health spending as a percentage of GDP (8.6%) appears moderate by international standards, this is helped by Australia's relatively young population. If Australia had the age-specific rates of expenditure that the UK has, Australia would spend 30% less.

## **The future?**

Policymakers are still searching for a sustainable funding system for long-term care. More use of user payments, hypothecated taxation and long term care insurance are all being explored as options. The coordinated care trials are being watched carefully for evidence of savings and cost-effectiveness. A test of whether the policy

framework is working will be whether a diversion away from residential care can take place without large additional amounts of public expenditure.

## C1.2 Strategic Framework for Delivering Long-term care

Australia has a national strategic framework for delivering long term care. A National Healthy Ageing Strategy has been agreed by Commonwealth, state and territory ministers in the last couple of years. This sets out a vision for 'healthy aging' of the population which:

"recognises the need for a coordinated and holistic policy and planning framework across all government agencies to ... respond ... to the diverse needs of older people and the challenge of the 21<sup>st</sup> century"

The strategy aims to "ensure that policy, programmes and service delivery are better coordinated across jurisdictions and agencies, and that resources are used more efficiently.

Australia is currently retreating from a process of devolving programme responsibility to States under the auspices of the Coalition of Australian Governments. In health and aged care, the Federal Government is keen to assume more responsibility. Simultaneously, however, it is government policy to expand the coverage of private insurance (or arrest its decline!) and legislation has just been passed giving tax breaks to individuals with private medical insurance. To date, the numbers taking up and staying with private medical insurance since the policy was announced has not been large (around 25,000). This policy was implemented in the UK under a Conservative Government in the 1980s and had only a small impact on the take-up of private medicine, while costing the Exchequer significant sums.

In the 1996-97 Budget, the Australian Government announced a major package of structural reforms to long-term care. This was motivated by various factors: the aging population, a drive for a more equitable funding system for people accessing residential care, the desire to enable aging in place and the need to improve the quality of (mainly residential) infrastructure. The new arrangements came into effect in October 1997.

It is important to remember that while the over-70 population is growing 214 times (and the over 80s 3 times) faster than the total population, only one in 10 of the over 70 population are in nursing homes or hostels, with a further 11% receiving home and community care services at any given time. Four-fifths of the elderly are managing in their own homes with little or no formal support. The twin policy issues in aged care are therefore how to provide (preventive) support to the vast majority of the elderly who are either healthy and are currently relying on informal care alone and, second, to provide timely, relevant and high quality services to the smaller proportion of elderly people needing formal care.

A key plank of the policy response to the aging population in coming years is to improve the health and well-being of older people by encouraging older people to remain economically active, to plan properly for years of retirement and to extend their contribution to family and community life. Australia has some way to go in all these areas. For example, along with particular rural and ethnic challenges (the life expectancy of Aboriginals is nearly 20 years lower than the rest of the population), Australia has the lowest workforce participation rate of males over 55 in the OECD

area and a low rate of personal savings. The contribution of the elderly to society (eg as carers and volunteers) has historically been undervalued.

Australian policy on aged care has incrementally sought to divert people away from residential institutions and into the community. Nursing homes were the dominant form of residential care until the late 1970s, catering for a broad range of dependency from minimal personal care up to intensive nursing care. Originally, 'hostels' (equivalent to UK residential care homes) were seen as a form of supported accommodation for older people and were developed in response to post-war housing shortages. Over the last 20 years hostels have increasingly taken on the role of providing personal and some nursing care to frail older people.

Initially, benchmarks were set at 60 places/1,000 people aged over 70 years in nursing homes and 40/1,000 over 70 in hostels (equivalent to residential care homes in UK). But over time the residential care benchmarks have been ratcheted down and now include a proportion of places in community settings. The latest benchmarks stand at 40 places/1,000 in nursing homes, 40 places/1,000 in hostels and 10 places/1,000 in home and community-care programmes. But the Government has recently announced that it will increase provision of community aged care packages to 12 per 1,000 by 2002-03 and 10% of places will receive a higher level of funding for people with complex care needs.

The Department's rationale for setting benchmarks is that it provides a sustainable framework for planning aged care services in the context of an aging population. It allows policymakers to set and monitor an appropriate balance of care between more and less intensive care settings and directly links the planning of care to the numbers of older people in a region. For example, under these arrangements, a limited number of new residential care places are advertised each year in regions of highest priority and (at least in theory) are awarded to service providers who can best meet local needs.

Another important innovation is the introduction of cross-boundary-care Aged Care Assessment Teams (ACATs), whose inspiration came from models of care in Wisconsin and Kent, UK. Initially, these teams were set up by direct grant from the centre, though they are now jointly funded by the Commonwealth and states. There are around 200 ACATs across Australia, usually located at or near health premises (typically local acute hospitals). Roughly half the clients who end up accessing community services will have come through an ACAT.

The teams are functional in nature and comprise nurses, social workers and occupational therapists, which allows them to provide multidisciplinary assessment, advice and referral services to a range of clients. ACATs are funded to act as gatekeepers to care, approving people for different forms of residential care or CACPs, based on their care needs. They have therefore proved a useful tool for diverting people into community care where appropriate and feasible. The Government is convinced of their usefulness and has announced an extra \$14 million to allow them to keep pace with the growth in the elderly population.

### **C1.3 Roles and Responsibilities of Different Agencies**

Services to older people involve all three tiers of government - Federal, state/territory and local government. At the Federal level, responsibility for health, aged care and disability services, until recently combined in a single Department of Health and Family Services has been re-split up into a Department of Health and Aged Care (with a separate Health Minister) and a Department Of Family Services. It appears that many of the ties between health and aged care have been severed in practice. Whether this is good or bad for coordinated care for the elderly is as yet unclear. At one level, it could mean that aged care is not 'captured' by health interests, but if aged care were the junior partner in a combined ministry, that could adversely affect the interests of the elderly.

At state level, the composition of ministries varies, but state health departments are generally broader in scope than at national or local government level in the UK. Both Victoria and South Australia have a Department of Human Services which encompasses health and social services. In South Australia, the span of responsibility is wider still - health, housing and family & community services are all brought together. In contrast, New South Wales has separate Health and Aging & Disability departments, but they are increasingly working closer together.

Broadly, the Commonwealth provides:

Medical benefits for private practitioner services, through an 85% rebate on a Government schedule fee, including private psychiatrists on a time-based fee for service. Although the Medical Benefits Scheme (MBS) pays on a largely uncapped fee-for-service basis, Australia has supply side controls on the number of medical practitioners by limiting the number of places in Australian medical schools (in public universities). Furthermore, to attract MBS rebates, all specialist consultations must be referred from another medical practitioner, usually a GP;

Pharmaceutical benefits for about 500 kinds of drugs in more than 1,800 formulations - including subsidies for a wide range of psychotropic drugs. In 1996/9, 124 million prescriptions were subsidised (around 65% of all prescriptions in Australia) - nearly 7 prescriptions for every man, woman and child in Australia;

additional, complementary programmes for war veterans and Aboriginal and Torres Straits Islanders - who are still eligible for mainstream services.

State and territory governments provide:

Inpatient beds in public hospitals (including psychiatric hospitals and psychiatric beds in general hospitals);

Community-based health services (including mental health services);

Community residential services (ditto);

Accommodation, rehabilitation and social support services provided by non-government organisations.

Private health insurance and other non-government sources provide:

private hospital services;

rebates for selected services provided by non-medical practitioners (eg psychologists).

#### **C.1.4 Financing Arrangements and Accountability Mechanisms**

In recent years the Commonwealth, in stark contrast to the US Government, has shown an appetite to increase the funding of home and community care. The Commonwealth co-funds community care with states, including support for carers. Overall, it provides 80% of the funds for long-term care and is primarily responsible for income support payments.

Funding for residential aged care is clearly the responsibility of the Commonwealth Government, which spent four-fifths of its resources - \$2.9 billion - on residential services (\$2.3 billion for nursing homes and \$0.6 billion for hostels) in 1997-98 out of total Aged and Community Care spending of \$3.7 billion. The state governments do not generally have a role in funding residential aged care, other than as service providers, and they have increasingly moved away from this role. Today, the vast majority of residential care facilities are operated by private or charitable groups.

GP remuneration is quite different way to the funding system in the UK, which has implications for the treatment of the elderly. There is a 'scheduled fee' for a GP consultation, 85% of which is paid to the GP by the Commonwealth Government (MBS Fund). On top of this, the GP is allowed to charge any of their patients a variable co-payment which is usually greater than the difference between the full scheduled fee and the 85% payment. However, most GPs do not ask for co-payments from those who have a health care card - mainly pensioners and those on social security. For these patients, GPs 'bulk-bill' the MBS. The incentive for GPs to do this will be greater the more competitive the market for GP services in an area.

#### **C.1.5 Service Delivery Models**

As in the USA, where states prize their political independence and are proud of local heritage and traditions, service delivery practice varies widely. The Commonwealth, by sponsoring innovations and pushing best practice models, has provided useful policy leadership.

Two Commonwealth-initiated community-based programmes - Home & Community Care (HACC) and Community Aged Care Packages (CACP) take the UK model of client needs assessment and service provision and expand its dimensions both horizontally to encompass both health and social care - eg bringing together district nursing and meals on wheels - and vertically, through greater involvement with elderly clients (see also Co-ordinated Care trials). These models have some significance for the UK, especially as they were bred out of UK (Kent, etc)



experience. The system is, however, still struggling to work out how to help residential care providers make the transition from relatively intensive to community settings.

### **1.5.1 Home and Community Care Services**

The origins of HACC services lie in the move to deinstitutionalisation in the 1970s. Patients were discharged from hospitals into nursing homes, and the cost was picked up (as in the UK in the 1980s!) by the Federal Government. But this situation gave states very little incentive to move residents out of institutional settings. So Aged Care Assessment Teams were therefore brought in to control access to nursing homes and provide alternative care services to clients in the community. HACC largely uses not-for-profit providers to deliver services. So far, no standard fee guidelines have emerged, and services are loosely means-tested with much variation in practice.

Total funding for HACC services is \$780 million, with the Commonwealth providing 60% of the available funds. There is a plethora of organisations providing home and community-care services. There are 4,000 HACC funded organisations alone - around 1 organisation for every 4,500 Australians - serving nearly half a million people a year. At any one time, 230,000 people are receiving HACC services, 40% of whom are aged over 80 years.

Services for the elderly include: community health services, such as home nursing (22% of spending and the largest single service); allied health care (OTs, physiotherapy, podiatry and speech therapy, etc); a range of fairly traditional social services such as home help and personal care, delivered meals, transport services, day and respite care; other services such as home modification and maintenance, neighbour aid (funds volunteer services) and dementia counselling.

HACC services have undergone a relatively recent reform in response to perceived problems, including long waiting lists for access to HACC services, eg domiciliary care. In 1994-95, an Official Committee was set up to review the efficiency and effectiveness of HACC services. It focused its recommendations on two broad areas of improvement:

- administrative changes to streamline the bureaucracy. A new Commonwealth and state agreement was struck in July 1997, which replaced the old system where states needed to get approval from the Commonwealth;

- a series of programme reforms concentrating on better assessment methods, output-based funding, competitive tendering, more attention to carers and a focus on quality and standards of services.

The two largest states - Victoria and New South Wales - have roughly equal-sized HACC programmes \$230 million and \$260 million respectively. In Victoria, local government often acts as the HACC provider. In NSW, services for the population of 6 million are provided through 16 geographic areas, which are identical to area health service and Department of Community Service boundaries, working through local not-for-profit agencies. Both models have their drawbacks - in Victoria,

criticisms centre around excessive bureaucracy, while in NSW, the problem is more with a diaspora of different incompatible, but fiercely independent, local providers.

In NSW, HACC administrators are working with the Department of Health to get joint planning of community and mental health and aiming for a single population plan across health and ageing & disability departments. The philosophy is to have clear service protocols that allow local flexibility and variation. A variety of service delivery models - including of integrated care systems - have been trialled in NSW.

### **1.5.2 Community Aged Care Packages**

In addition to funding available through HACC providers, ACAT-accessed and Commonwealth-funded Community Aged Care Packages (CACPs) provide people with complex care needs (who previously would have been placed in residential care) with a tailored package of personal care services in the community. (For an example of a good service provider see Mercy Family Services in Best Practice section.) One of the main advantages of CACPs for individuals is that they allow the person/family to deal with just one person who arranges all their necessary care. The advantage for policymakers/funders is that they provide appropriate services in preferred settings, usually at less cost than residential care.

There were just over 10,000 CACPs in operation at the end of March 1998. In April 1998, the Minister for Family Services approved an additional 3,800 CACPs and an additional 3,760 CACPs through hostel conversions over 4 years to 2001 at a cost of \$95 million. The plan is to reach a target of 12 CACPs per 1,000 people over 70 by 2002-03, which would translate into around 18,100 packages. This implies a very significant expansion of the programme.

But before celebrating a major diversion away from residential care settings, this increase needs to be seen in the context of growth in the number of nursing and residential care beds from 138,000 in 1997 to a forecast of over 150,000 by 2001. Seen in this light, the expansion of CACPs represents a fairly small overall impact on the location of care - still around 90% of people would be cared for in institutional settings.

For people living in rural areas, access and choice are inevitably more limited and multi-purpose services have been set up to meet the community's needs - see Otway Home & Community Services in Best Practice section as an example of an MPS provider.

## **C.1.6 Broad Policy Debates**

### **1.6.1 Cost shifting**

As has been noted, the Commonwealth funds the bulk of GP services, drug costs through the Pharmaceutical Benefit Scheme (PBS) and institutional care - care in hostels (equivalent to residential care homes in the UK) and nursing homes - while states run and pay for hospital services and co-fund community care services. Since demand for care invariably outstrips available funding in these settings, each sector of government tries to shift costs elsewhere.

For example, states will try to divert patients from outpatient clinics and hospital emergency departments to GPs (as in the USA) and will similarly attempt to shift drug costs into the community. States equally believe the Commonwealth has shifted costs onto the jointly funded community care/HACC sector by restricting the number of nursing home places. This is reminiscent of the cost shifting between acute and primary care in the UK and the dispute between health agencies and social services as to who should meet the cost of home care services.

A clear demonstration of the problem in Australia is in planning post-acute care discharges, whose quality is still variable with some hospitals either not doing discharge planning or failing to use trained social workers to draw up plans.

### **1.6.2 Quality of care and outcome measurement**

A system of outcome measurement was put in place in 1987 and evaluated in 1993. Subsequently, though, this approach was replaced in favour of an accreditation system with industry self-regulation. The Australian Institute for Health and Welfare has developed quality standards for HACC programmes and has been commissioned to develop measures of client satisfaction. Discussions with policy makers and practitioners reveal some confusion between outcome and output measures, with the latter sometimes (wrongly) referred to as examples of the former.

Any satisfactory quality measurement system will probably need to use a mix of indicators, including client satisfaction surveys and clinical indicators such as length of stay, as well as management techniques such as monitoring compliance with care protocols.

### **1.6.3 Service linkages**

There are several examples of attempts and pilot programmes to better coordinate health and social services. One example is the effort made by the Victoria Department of Human Services, which has recognised that the fragmentation and poor coordination of its services requires remedial action. Others include the development of multi-purpose services in rural areas and the Australian coordinated care trials. These are explained below.

## **Cross-programme partnerships in Victoria**

The Department of Human Services in Victoria has realised that there are natural

linkages, based on commonality of client groups, between the Aged, Community and Mental Health Division (ACMH) and Youth & Family Services, Disability Services, Acute Health Services and Housing. There are also client groups that require a coordinated response from ACMH, eg people with both mental health and drug abuse problems. A programme of partnerships is being developed which includes the following initiatives:

common approaches to service planning, purchasing and delivery among primary health and community support agencies. It is expected that service linkages will improve through appropriate assessment, referral and information sharing;

the development and implementation of a 'Working Together' Strategy for improved and integrated service delivery to joint clients of Protection and Care, Mental Health and Drug Treatment services. The strategy will be based on guidelines to assist in improved collaboration between staff of the relevant services, pilot 'service enhancement' models and joint staff training;

the expansion of the **Multi Purpose Service programme** (see specific section below and Otway Health & Community Services Best Practice Example);

two dual disability demonstration projects that aim to enhance treatment interventions for clients with both brain injury and drug/alcohol problems;

a two-year project to establish a dual diagnosis team to improve service delivery to clients who require both mental health and drug treatment services;

the Complex Care Initiative, which enables packages of care to be assembled for people with complex or multiple needs who need access to services from a range of Department of Human Services programmes. Target groups include older adolescents and adults with problems of homelessness, drug/alcohol abuse, mental health problems and chronic illness.

## **The Australian coordinated care trials**

This is one of the most interesting international innovations at the health/social care interface, at least for people with multiple disabilities. It is also radical in the Australian context as health and community services are currently characterised by multiple programmes, each of which has their own approach to rationing, waiting list criteria, etc. The trials therefore hold out the promise of a more rational and consistent approach to allocating services to clients.

In 1995, the Coalition of Australian Governments authorised 9 coordinated care trials whose aim was to improve the quality of care delivered to older Australians and make access to services less dependent on local and national funding vagaries. These trials enable the Government to test:

the **pooling of funds** across a range of funders and services;

the **pooling of clients** who access a plethora of agencies and providers despite meeting common criteria;

the **testing of different coordination models**, including formal care coordination, care planning, services coordination, public health initiatives, linking information systems and implementing best practice guidelines.

The trials have been given considerable latitude to develop their own approaches to coordinated care with very general set parameters. This was probably deliberate - to allow a wide variety of models and experience to emerge within the trials and get as much information as possible on which to base subsequent decisions in the area of integration. In the trials, one organisation is given responsibility and the budget for providing all of the care required for its client group in its catchment area (NB not all trials involved elderly patients).

The real innovation is that Commonwealth and state funding is pooled (around \$3-10 million per trial) and the organisation has total discretion over how and which services are provided. Fund pooling was intended to be a way that trials could bring different programme funding together and impose a single service allocation tool consistently across a set of clients. But several trials in fact did not pool funds at all from the community sector, and others had difficulty getting the hospital sector to pool funds.

The trials were initially marketed as 'managed care' trials, but this message was turned down because it engendered concerns about cost cutting. In any event, significant tensions between the health and community care sectors existed in the early days of most trials. For example, the community care sector felt that the acute sector would try to suck money away from community care.

### Interim findings

The trials concluded in January 2000, and a full evaluation was completed in March 2000. The full evaluation has not been seen by the author, but there was an interim evaluation, and early findings suggested that two broad issues were emerging:

Costs. Can the trials create savings - by preventing hospitalisation and/or reducing lengths of stay - in order to pay for the additional HACC services provided or the additional care coordination costs?

Service improvement. Do the trials change the way HACC services are provided so that a better mix can be delivered at the same cost or change the methods used by agencies to provide services, which lowers the unit cost of providing that service?

Most of the trials that included HACC services achieved these goals to some extent. But it has proved very difficult to judge cost savings as it has been hard to construct a satisfactory counterfactual case or economic cost benchmark, eg the expenditure that would have otherwise been incurred over the two years of the trial across all clients and their services. Consequently, it has been very difficult to prove that, for example, hospitalisations have decreased.

One commentator - Professor John McCallum has raised concerns about the extra costs of administration, ie the costs of care planners and the cost of satisfying previously unmet needs recommended by care planners. This seems valid according to the interim evaluation. Infrastructure costs are averaging out at 35% of total trial expenditure. Of the remaining 65%, a further 15% on average was spent on care coordination (spending here varied from 8% in trials where GPs performed this role to 23% where care coordinators were hired to undertake intensive functions).

Other problems include:

the steep learning curve on fund pooling that institutional participants have had to climb. Two states refused to pool hospital and community funds, and the Commonwealth ended up paying the hospital contribution for Tasmania;

the failure to pool funds from the community sector. Several trials experienced problems due to the limitations of IT systems and the difficulty of negotiating with small agencies;

the potential to exhaust all local volunteer services. If the trials successful in changing care patterns it can make such a big demand on HACC services that it can soak up, and exhaust, local volunteer care capacity.

Nevertheless, if early indications suggest that the programme is proving useful and/or yielding savings and improving care (different models are being tried), then the Commonwealth Government is likely try to roll it out more widely. The Government will be on the lookout for eye-catching initiatives in the International Year of Older Persons and the years beyond to address the needs of the elderly. Coordinated care is therefore a natural candidate for expansion.

To this end, in the Budget in spring 1999, as part of the deal for securing other aspects of the Government's programme, the Howard Government allocated an extra A\$35 million for extended coordinated care trials and legislated to include two new Medicare (MBS) items - multidisciplinary care planning and case conferencing - that GP's can claim from the Health Insurance Commission. Previously, GPs were paid little or nothing for these activities, unless they were salaried, which few are in practice. Unfortunately, this focus on the role of GPs - a feature of only some of the trials - distracts attention from fund-pooling and involvement of other care professionals, where the evidence suggests more gains are likely to be made.

#### Specific lessons from two coordinated care trials

I visited the sites of a third (3 of the 9) of the Australian trials: the Mercy Family Centre operating in New South Wales, the Bundoora Extended Care Centre in Victoria and Care 21 in South Australia (see Best Practice section for details of two of these trials). The coordinated care trials provide an opportunity for the Australian Government to trial and evaluate far-reaching service reform.

Several issues have emerged from these particular trials to date:

first, the role of GPs. A key finding of this attempt at integration, as with other international examples, is that they are crucial players. But while some GPs have proved to be competent and enthusiastic participants, the evidence to date does not suggest for a variety of reasons that GPs want to be, or make, good care coordinators. Care 21 attempted to address the role of GPs directly, by discussing the GPs main concerns that they would be excluded from reassessment meetings, where clients had negligible medical components to their care, and that GP consultations and income would be reduced as a result of the trial. This process of dialogue has resulted in better relations, and 150 of the GP division's 200 members are now actively participating in the trial, but crucially they are not acting as care coordinators;

second, the funding arrangements for the trials. Initially, funding for the trials was in the form of capitation payments with residual funding for 'outlying' clients eg those with unexpected or very high cost acute medical needs. But it was found that this funding regime led to overspending and consequent inability to meet needs. An overall trial-level budget (between \$3-10 million) has therefore been imposed instead;

third, difficulties in changing behaviour. The evolution of the trials and changes in behaviour have reflected the initial orientation of the trials. Pooling funds seems to be a necessary, but not sufficient, condition for delivering integrated services. If money is pooled and the 'labels' taken off the dollars, but the behaviour of key agents is not changed, then 'labels' go back on money and services. The key to successful cross-boundary working appears to be selecting good coordinators/professional care workers and then, crucially, incentivising the players to accept changes in working practices.

According to evaluation to date, the keys to getting the trials to work appear to be changing participants' behaviour and 'labels' on programmes; providing integrated funding to integrated teams; allowing comparisons between groups and across geographical and operational boundaries. If the trials work, they will do so because they allow people planning, coordinating and delivering care to look at the total cost of care and make appropriate short vs long-term care/cost trade-offs. An important question, which has yet to be resolved, is the population group for whom coordinated care is likely to be worthwhile and beneficial. It is possible that it will only be really effective for a very limited number of people with complex care needs.

It is still early days in the history of the trials to determine whether fund pooling works. The operation of one of the trials - in the Hornsby Ku-Ring-Gai area of North Sydney - clearly shows that it is possible to create a fund pool and have a surplus *in the short run*. But the mid-term evaluation of this trial states "the extent to which the fund pool is able to provide a viable source of funding for all care needs of participants in the future is less clear... whether the surplus currently being generated from the fund pool is a true 'saving' resulting from the coordinated care approach, or simply the result of 'gaming' or incorrect estimation of funds by some of the pool contributors."





## Care coordination in another guise - Multi Purpose Services

This is an example of how to provide health and community services from a single site (or a few sites) under one budget. The origin of the Multi Purpose Service (MPS) programme lay in the recommendation of the 1991 Joint Aged and Health Care Taskforce that there needed to be more flexibility in the delivery of health care services to rural communities. To achieve this, the Taskforce recommended that existing Commonwealth and state funding for health care services should be pooled and re-allocated to meet each community's needs.

The MPS programme was piloted from 1992 and expanded as an ongoing developmental programme in 1994. The types of services and organisations vary substantially. In Victoria, three communities - Apollo Bay, Corryong and Orbost were initially selected to run an MPS programme. There are now 30 MPS services in Australia, of which 6 are in isolated areas of Victoria (with two more under development). They were designed to solve two problems facing rural communities - a lack of service coordination and the fact that the small scale of the communities often meant it was uneconomic/not feasible for services to be provided to them.

The advantages of MPS are a bit like those claimed for GP fund holding and/or primary care groups in the UK, namely:

the organisation is a one-stop shop - people don't have to 'shop around' for care providers;

services are client focused (rather than the person having to fit the service);

it is a 'total' service and so allows community and residential services to be flexibly provided (eg Christmas lunch can be provided at home or in a centre);

similarly, co-located acute and residential care allows people to receive medical care without being dislocated;

it is a financially efficient model, ie it saves on management/staff overheads by avoiding duplication of senior officers, receptionists, accountants, etc.

The MPS philosophy and objectives are to improve the flexibility, cost-effectiveness, targeting and coordination of health and aged care services both locally and regionally. The catchment area must be clearly defined - eg a single town and its district. The programme strives to bring together funding for all health and related services in an area into a total MPS funding pool, which is managed by the community. Typically, Commonwealth funds (HACC, Aged Care), state funds (hospital, community health, HACC) and local government funds are pooled to provide a very wide range of services including:

- community care;
- community health;
- basic acute care;
- residential care;
- mental health care;

health education & promotion;  
high dependency community care (nursing home facilities);  
child health care (including day care).

In practice, this means that bodies and organisations as diverse as residential care and nursing homes, hospital, community health services, local government, primary health care services, GPs, allied health providers, the ambulance service and relevant government departments at all levels need to be involved.

Where some services cannot be integrated into the MPS, the programme insists that strong links be established so that services are provided cooperatively and with maximum co-ordination. The MPS must be administered by a single board of management, responsible for all MPS funds. A variety of models for the location of facilities (eg a single site, on more than one site in the same town, in one town but with services linked to non-MPS services or in more than one town) are allowable. But, irrespective of the physical service configuration, staff and bed flexibility, multi-skilling and the movement of staff between services is essential.

The most functionally efficient model appears to be where hospital (including ambulances), nursing home, hostel (residential care), day centre, community, preventative and educational services are provided from a single site - usually in the most populous part of the catchment area. It is the firm view of those involved locally with MPS services that case mix or output-based service funding does not work in rural areas.

The Multi Purpose Service concept is a powerful example for other countries of how to run health and community services for remote and rural communities. It has strong central and - where it has been tried - local support. Problems include issues of service coordination within and between services and scale. The main disadvantage is that the service will inevitably end up as a local monopoly provider, with the possible problems associated with this - price fixing, 'cream skimming' and denial of service. But their strengths seem to outweigh this weakness, namely:

more appropriate services: MPS is a cutting-edge concept - it is explicitly client-centred in operation (service fits clients not vice versa);

more responsive/accountable: it allows one local health/community care organisation to respond in a flexible way to the identified needs of the community. From the purchaser point of view, local systems often get more commitment from their staff and give better value for money;

greater choice: it allows a wider range of health/community services to be provided locally (usually in one location) than would normally be available.

There is an interesting issue as to whether the Multi Purpose Service concept could (or should) be extended to a sub-regional, or even suburban level. In practice, one of the real problems in integrating acute and community care lies in the administration and monitoring of acute care. Decentralisation of secondary acute care is often an anathema to current bureaucratic and funding systems.

Another issue is where MPS organisations would be located if the MPS model is generalised. Though superficially attractive, it is not clear this concept is transportable into high-density areas, where functional specialisation is more feasible. If they were to be located in towns, then how does the MPS concept differ from rationalising the services that are already provided onto fewer, more explicitly-linked sites, eg putting nursing homes and hospitals onto the same site? Is it necessary, practicable or feasible to bring together financial and employment advice, diabetes counselling and podiatry under the same roof in a non-remote area? Where do economies of scope outweigh the greater efficiency/effectiveness from service specialisation?

## Comments and conclusion

Problems with the Australian long-term care system include:

funding and policy is still largely split into acute health, primary care and community care 'silos' which frustrates policy integration;

there is arguably too much bureaucracy - there are over 60 separate Commonwealth health programmes along with a plethora of State procured services which leads to confusion and difficulties in coordinating services;

the historic problem of cost-shifting between Federal & State authorities still rears its ugly head, eg the care of the elderly mentally ill. People with mental illness are the responsibility of states, while aged care is funded by the Commonwealth, and disputes result over who should assume care costs.

But on the positive side, the Australian long-term care system can also be considered to be more consumer-focused than most other countries. Three main forces are pushing (and will continue to push) in this direction:

the operation of Community Aged Care Packages and Aged Care Assessment Teams require the development of individual care plans. These programmes are being expanded;

there is a powerful consumer health forum which acts as an umbrella group for disease specific groups. They have representatives in each state and have good access to Commonwealth policymakers, eg they were represented on the Australian Pharmaceutical Advisory Commission, which among other tasks drew up guidelines on discharge planning;

compulsory superannuation (6.5% of salary) which is levied and passed to a fund for individual medical care.

The major problem for integrating care in Australia is the fragmentation of funds, in contrast to New Zealand where arguably the biggest problem is the fragmentation of primary and secondary health care providers (but see Eldercare Canterbury in New Zealand Best Practice section for a counterexample).

The coordinated care trials represent a set of attempts to solve this problem. The

benefits of the trials look at the moment as if they outweigh the problems. The benefits appear to lie in two main areas:

fund pooling, by changing relative prices between health and social care providers, ought to lead to savings from more efficient and effective provision. However, there must be some doubt about this outcome and that freed-up resources will go to increase quality instead;

improved access by the elderly to much-needed community services will reduce hospitalisation rates. The evidence seems more supportive here.

Finally - a cautionary note (not meant to be unduly critical): Australian innovations are more visible than they are in Europe, where there is a thicker network of services and higher population density, and this may lead people to overestimate progress in care assessment, provision and management.

## **C.1.7 Best Practice Examples**

### **Example 1: Otway Health & Community Services - an MPS Service**

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Otway Health and Community Services (OHCS) is an independent health & community care provider operating in a rural area of the State of Victoria. It was created as a Multi Purpose Service (MPS) on 1 January 1995. In the mid 1990s, the community's stand alone hospital facility - the Apollo Bay and District Memorial Hospital was faced with closure. To save the hospital, a group of local people representing all the health and community services within the shire of Otway developed a plan to run an MPS. \$1.8 million of state capital funding was received for the redevelopment of facilities (including \$300,000 for a new community health centre) to enable all services to be drawn together in one location.

Apollo Bay is a small seaside tourist resort town in South West Victoria, 180 km from Melbourne, with its nearest major referral centre - Geelong - 120 km away. The area has a catchment population of about 3,800 people, of whom nearly a fifth - 17% - are aged over 70 years. But this conceals a dramatic seasonal population swing. The local region has a permanent population of about 1,200, but this swells to 25-30,000 over weekends, summer and school holidays. The resort is located on a busy interstate route (the Great Ocean Road) which also makes its own demands on Otway's A&E service.

The core of OCHS is formed by the 12-bed Apollo Bay Hospital, a 15-bed residential care facility, a separate nursing home with 4 high level care beds, the Community Health Centre (primary care) Community Centre (family support) and Otway's Home & Community Care Services. The organisation receives set funding for a 3-year period.

In the A&E service, a doctor either deals with the patient direct or stabilises the person before dispatch by ambulance to the main acute facilities in Geelong. Home-based care is provided through the Commonwealth's Community Aged Care Packages (CACAP) Programme. Referrals come to OCHS from a service based in Geelong (St Lawrence Community Services Inc, 78 Gheringhap Street, PO Box 1772, Geelong, Victoria 3220). Otway is also a 'subcontractor' for post-acute care, eg nursing care and physiotherapy, etc.

Establishing an MPS seems to have brought many benefits, including:

a secure and financially viable future for local health & community services;  
flexibility to introduce new, bigger, different services as needs change;  
inclusion of a new long-day child-care centre;  
the provision of local dental services after a long period without them;  
formal psychology and counselling services.

Perhaps the most surprising feature of OCHS's services in Apollo Bay and the surrounding area is their amazing diversity within such a compact physical location. It is difficult to do justice to the extent of services provided. The full list of services runs to 73 distinct services, ranging from an A&E Unit and minor surgery, postnatal care, diabetes management in the home, a 40-place child day-care centre, pedicures and massages to a range of home and community care services, including social work services, delivered meals and home maintenance.

The main client pressures are in the area of residential care, since local people still appear to be of the view that the best care is in residential care and are keen to secure a 'place' when they perceive they cannot cope at home. OCHS do not means test for admission to a care bed, though if someone has assets over \$75,000 they ask for a \$50,000 donation which is invested on behalf of the client, who receives the interest during their lifetime.

## **Example 2: Care 21 - a Coordinated Care Trial. South Australia**

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Care 21 has been operating since September 1997. It is included here as an example of a project being run as part of the Australian Coordinated Care Trials (see issues section on coordinated care), which is an initiative of state and Commonwealth governments.

### The philosophy and hypotheses behind the Care 21 trial

Care 21 is the only community sector based trial in Australia and is sponsored by the South Australian Department of Family and Community Services. It has been operating since September 1997 and was due to be completed in December 1999. Its focus is to provide a more coordinated approach to care for people over 65 in the northern suburbs of Adelaide. The unique feature of the trial in the Australian context is that client eligibility is not determined by diagnosis, but rather by complexity of needs, which suits an older age group well as they often have complex co-morbidity in relation to their health problems. The main benefits of the trial seem to be:

- people 'owning' their care plan and contributing to their own needs and goals;
- including the GP as an integral part of developing the care plan;
- having a coordinator who has an overview of all aspects of the consumers' care, working in conjunction with the GP and all community services;
- perhaps avoiding unnecessary hospital admissions.

Participants (around 500 people to date) in the trial have an individual case plan and a package of care based on their requirements. The package provides continuity throughout the health and community-care system and involves GPs, hospitals, specialists, pharmacists, allied health professionals and community service providers. It also acknowledges the importance of addressing carers' needs. As a corollary to Care 21, a model of single assessment for services to the aged in the northern suburbs of Adelaide is being developed.

The trial is designed to meet the needs of a local aged (65+) population with complex needs. Previously, these clients experienced difficulties obtaining services

due to:

- multiple entry points to services;
- eligibility restrictions and long waiting lists;
- difficulties negotiating the complex/fragmented community care sector;
- limited knowledge of, and information about, available services;
- language and cultural barriers which frustrated access.

Accordingly, the focus of Care 21 is to coordinate services for the individual elderly person, eliminate the need for repeated assessments and provide a seamless model of case management from the pooled funds of participating services. The trial aims to create a continuity of services between the clinical and community care sectors. Specifically, by including GPs explicitly in community care decisions, it seeks to build new relationships between community services, GPs and major care providers. The greatest challenge has been to eliminate the boundaries between service providers without adversely affecting the service providers concerned.

The main hypothesis tested by this - and other - trials is that:

"Coordination of care for people with multiple service needs, where care is accessed through individual care plans, and funds are pooled from existing Commonwealth, state and joint programmes, will result in improved individual client health and well-being within existing resources." (*New Horizons for Care*, Care 21, March 1998)

This hypothesis, along with a variety of more detailed secondary hypotheses (eg "that the success of coordinated care will be affected by the characteristics of the clients to whom services are provided") are being investigated by local and national evaluation teams.

The Care 21 care coordination model was developed using a collaborative approach by a team of people whose working experience covered a range of community service agencies with the aim of offering a new degree of flexibility, choice and options that is also inherently consumer focused. The model is unique in splitting the care planning (planner employed by Care 21) and service co-ordination (tendered out to existing primary/community care agencies) into two discrete roles. One of the advantages of having service coordinators from a variety of agencies is the natural cross-pollination of knowledge between the agencies.

The process is as follows: after clients are assessed and enrolled in the trial, their service needs are identified and a service package to meet those needs is then planned and implemented. Perhaps what distinguishes this model from the mainstream model is the active intent to "empower the client to explore their options and to articulate their goals and needs, so that they may actively participate in a care plan that meets their requirements" (Care 21, op. Cit.). As part of this client-centred objective, a consumer reference group exists which provides feedback on the trial direct to the Director.

There are 7 formal steps, in four phases, in the care coordination process:



assessment: meet entry criteria -> construction of a consumer profile -  
 >  
 service planning: development of a care plan -> service implementation ->  
 service review: monitoring -> reassessment ->  
 closure: case closure

The entry criteria are straightforward: the client must be over 65 on 31/12/97 (55 for aborigines); live in the designated locality and "use or require support services at home such that they will benefit from care coordination". The latter (slightly circular) criteria were deliberately broadened from the original "clients using multiple services" so that people would not be deterred from applying and could be referred elsewhere if not appropriate for care coordination.

Consumer profiles draw together information from assessments conducted in the clients' home, data provided by GPs on the clinical side, existing client data from other, agencies, eg Royal District Nursing Service, domiciliary care service, etc. It records client needs for health and social services and the availability of informal care. Clients are streamed into 3 levels of clinical and care protocols - low (stable medical condition, requiring low intervention residential care), medium (with an unstable medical condition at risk from needing more extensive/intensive care) and high (unstable medical condition requiring nursing home level of care) -with an estimated average annual budget of \$3,500, \$7,000 and \$11,000 per capita respectively. The ratio of clients in these categories is expected to be 50:35:15.

Care plans are linked to the protocol level determined at the assessment stage. The use of protocols, and the involvement of the GP, is built into the process at the outset. After a meeting to discuss the proposed care plan at the clients' home, the allocated 'Care Planner' draws up a matrix of clinical and community care needs against health and wellbeing goals, which have recorded outcomes and target time frames.

The care planner then determines the cost of the care plan and passes the plan and the budget to a 'service coordinator' for service implementation. This function is tendered (to minimise costs to the trial and widen client choice) and is being performed by a variety of providers, including large existing community care providers (eg RDNS, etc), GP sites or council-based home-assist services. The coordinator has a maximum budget with which to purchase a care package. In this model the relationship between the service coordinator and consumers is critical to the success of the model.

The monitoring procedure is relatively formalised with the frequency of visits/phone calls ascending from every 8/4 weeks in the case of a low-needs client to every 2/1 weeks for a high needs client. Information is fed back to the GP, who in any event reviews the clients' care plan twice a year. Need reassessment takes place at least 12 months after enrollment. Case closure occurs if a client chooses to leave the trial, becomes a cost 'outlier', dies, or the trial comes to an end.

Some other interesting initiatives have taken place within and alongside the trial itself covering GOP involvement, pharmacists and prevention work:

Care 21 has developed a programme called 'Healthy Scripts', where a GP can write a prescription for exercise as part of their care plan designed to achieve specific clinical outcomes for the person in the programme. One might question why a prescription (and associated bureaucracy) is required for someone to undertake exercise, but it is nevertheless welcome if it stimulates a more holistic approach to health care;

pharmacists in Adelaide are in the process of establishing a Division of Community Pharmacy, which will allow pharmacists to communicate regionally with the Division of General Practice. This will allow the two professional groups to discuss territory and turf issues without getting caught up in discussions at a national or regional representational body level;

A 'Partnerships for Wellness' programme has been created to address the needs of people with histories of frequent admission to hospital and those who have been admitted to acute care when lesser care would have sufficed. The programme is divided into 2 'streams': stream 1, which concentrates on prevention, seeks to develop more regular contact between GPs and high hospital-use patients; stream 2, focusing on early discharge, recognises that it may be difficult to predict who will be high users of hospital services and allows GPs to admit some of their patients to a low-level care facility.

### **Example 3: Aged Care and Housing Group - a Housing and Care Provider**

#### Contact details

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Aged Care & Housing Group (ACH), previously called Aged Cottage Homes, is a private not-for-profit organisation which was incorporated in 1952. It initially raised funds and built accommodation for the poor elderly. It now has about 850 permanent and relief staff, a network of 500 volunteers and has about 6,000 clients.

#### Philosophy

ACH is an aged care organisation experienced in developing new residential facilities and community programmes. It prides itself on its progressive vision for the future and in meeting the needs of the elderly in South Australia. It has traditionally had an approach of valuing the individual elderly person, building services around the individual, maintaining the elderly person's networks and building support so that the elderly have a chance of growth and connection rather than isolation and boredom.

A prime focus of their services is to create positive outcomes for the elderly and to shore up their community networks. Their hallmark has been a relatively high standard of care. According to the organisation's annual report "quality has been about developing procedures to ensure that we work consistently across the organisation." The organisation prides itself on staff development and training and consumer involvement.

#### Range of services

The range of services ACH provides includes:

- 5 nursing homes & 4 hostels (418 people);
- 195 community aged Care packages;
- 480 independent living units (600 people) in metropolitan Adelaide;
- 155 resident-funded housing units;
- 5 Community Options programmes;
- 3 health cooperatives providing rehabilitation, therapy & learning support (1600 people);
- one-off home support & home maintenance programmes (1,500 people per annum);
- GP Link: individual crisis support to prevent hospital admission (200 people);

neighbourly help, a club, 4 holiday programmes and consultancy services.

### Nursing home provision - Colton Court

ACH's original aim was to provide independent housing and it has hitherto operated mainly as a housing provider - operating a fairly large number of pretty traditional residential care, private and communal living arrangements. One nursing home - Colton Court - which I visited departs from the standard model. While not being as large, or as well designed as some of the very latest projects elsewhere in the world (eg see Humanitas, Rotterdam, the Netherlands), the project is relatively unique in design. The units provide a degree of independence that traditional nursing homes lack. Built in 1989, the project consists of 22 self-furnished cottage units that provide residents with their own bedroom, bathroom, living, dining and kitchen facility. Not surprisingly, Colton Court is more expensive than traditional accommodation in terms of construction and operating costs. It was built for \$1.9 million or \$63,000 per bed, compared to traditional nursing homes which could be developed for \$55,000.

Positive features of the project include:

each unit has its own front door, which opens onto a street frontage, and (unusually) a back door which opens into an internal service corridor through which meals can be delivered, linen and other staff services provided;

residents have the opportunity to live together with their spouse and retain their furniture and other valued personal possessions, as only a bed and kitchen equipment, vacuum, etc, are provided;

a stable team of multi-skilled personal care workers means that staff are able to give more one-to-one attention, minimising service intrusion and helping to build trusting relationships.

### Non-residential provision

In line with the international trend towards more independence for the elderly, ACH now operates substantial Community Aged Care and Extended Aged Care at Home (EACH) packages. The CAC packages have been described elsewhere (eg see Mercy Family Centre). The EACH programme provides support to the elderly person who has been assessed as needing high level care by providing services in their own home.

Another innovative programme is the GP Home Link programme which offers a package of community care (home help, nursing care, overnight assistance and use of specialised equipment) to prevent unnecessary hospital admissions which are only required because of the lack of skilled support in the home. With this service, a GP can rely on a team of helpers being available to help deal with a crisis. ACH also run an unusual holiday-instead-of-respite service. Wyatt Holidays provides assistance to over 60s in planning a holiday, can provide a travel companion and, in some circumstances, can provide some financial assistance.

## **Example 4: Mercy Family Centre. Sydney - an Urban Multi Purpose Service**

### Contact details

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The Mercy Family Centre has evolved over a period of 100 years from a small founding home run by largely untrained nuns into a large multipurpose organisation providing professional residential and community services in two locations in the Greater Sydney area - Waitara and Waterloo (The Mercy Arms). Reflecting its owners - the Sisters of Mercy - its core values are compassion, hospitality, mutual love and justice. Its mission is to "assist people to build communities which are just, innovative, socially creative and supportive of individuals and families". It translates these values into working with and advocating for the most marginalised and disadvantaged. The Mercy Family Centre recognises that society is constantly changing and seeks to adapt its work to contemporary issues. In particular, it recognises that care for older people is in a process of rapid change and that the trend towards services provided within people's own home has gathered momentum.

I was particularly interested in looking at the operation of the Community Care programmes - Community Aged Care Packages and HACC services - provided by the organisation. In addition to providing residential services, day therapy, family support and children's services, the Mercy Family Centre also runs the following community care services: Community Aged Care Packages (CACPs), a Community Options Programme (250 clients), a Confused Adult Brokerage Programme (33 clients), independent flats with access to on-site services, respite care provision, a dementia monitoring programme, dementia counsellors (over 40 clients) and community visitors (70 people). The centre also works with Jewish and Chinese service providers in Sydney. The Assistance with Care & Housing for the Aged programmes, dementia programmes, aged care packages and community visitors are all directly funded by the Commonwealth.

The Mercy Arms, based in inner Sydney provides services to the frail-aged community, including Community Care Packages and care through the Assistance with Care & Housing for the Aged programme. Mercy Community Care coordinators also continue to participate and provide input to the Linked Care - Coordinated Care trial in the Homsby/Ku-ring-gai area.

The organisation provides 60 CACPs in the form of flexible care plans, which allow a choice of services to meet the individual care needs of the elderly who wish to continue to live at home rather than enter residential care. Anyone who is over 60 years of age, is assessed by an Aged Care Assessment Team (ACAT) as needing hostel level care and lives in a relevant catchment area is eligible for a CACP. A

broad range of services are included in the package: showering/bathing, dressing, mobility/transport, preparing meals, laundry, housework, gardening, home maintenance, administration of medication, rehabilitation, emotional support, social activities, advocacy services etc. Client fees are negotiated on an individual basis. The Government allows the organisation to charge up to 17.5% of the pension (equal to around \$38 per week) - generally the organisation looks for a contribution of \$15 a week.

A typical CACP package would be provided to a woman in her 80s, living in a bed-sitter or one bedroom flat in a tower block. She might have a very limited social network, alcohol or drug problems, or dementia and would have been referred by her GP or directly from hospital, having first been assessed at home as eligible for care by members of a local ACAT. Practical details that need to be worked out include a precise care plan and deciding which carer will work with the client.

Mercy also provides help through the Assistance with Care & Housing for the Aged (ACHA) programme at their Waterloo site. The programme aims to assist poorer older people to access secure and affordable housing and get appropriate aged care support services, thereby allowing them to remain in the community. Eligibility is open to those over 60, in receipt of a government pension and homeless or living insecurely in private rented or public housing. A typical beneficiary of an ACHA package might be an ex-World War Two veteran, currently living in a boarding house hotel. The ACHA would fund a room (for about \$90 a week) or a Department of Housing flat and help with the move, cleaning, shopping, etc.

Problems with the CACP include confidentiality of nursing/medical details, communication between care staff and the lack of a unified administration (eg common form) for entrants to the programme. Mercy has a good interface with health providers, eg local community health nurses and CPNs who are lined in with ACATs. The organisation, however, has to pay local government (Sydney City Council) for meals on wheels and community transport, which is a significant drain on their funds. They gave very positive comments about the Commonwealth funded CACP and ACHA programmes.

## ANNEX 1: A DESCRIPTION OF AUSTRALIA'S HEALTH SYSTEM

### C.A1.1 The Overall Health System

The Australian health system is a mixed public and private system. Public hospital and most out-of-hospital medical services are covered by universal taxpayer funded health insurance; private hospital and a range of non-medical out-of-hospital services are funded through private health insurance or other sources of funding such as workers compensation insurance or individual co-payments. Under the Government-funded health insurance system, all Australians are eligible to be treated in public hospitals free of charge and to receive rebates on private medical practitioners consultations. 30% of the population have private medical insurance.

Total (capital and current) spending on health in Australia was A\$41.7 billion in 1995-96 - 8.5% of GDP. Health expenditure has grown in absolute terms and as a percentage of GDP compared to 10 years ago. Although over most of the decade, spending has been stable as a percentage of GDP, growing from 7.8% in 1989-90 to 8.6% in 1991-92 and has been stable at 8.5% since 1993-94.

Funding for health service provision is shared between the Commonwealth, state, territory & local governments and the private sector. In 1995-96, the funding breakdown was:

Commonwealth:	\$13.4 billion (34%)
State, territory & local:	\$13.1 billion (34%)
Private health insurance:	\$ 4.4 billion (11%)
Other non-government sources:	\$ 8.0 billion (21%)

#### Policy principles

Five key principles guide the operation of the Australian health care system:

universal access to health care, which will guide the level, mix and distribution of services to individuals;

provision of high quality care, commensurate with other developed countries;

equitable financing, with people paying for care according to their means;

a mixed (public and private) delivery and financing system (though the equity and universal access principles require a strong role for government in funding, planning and regulating health care);

accountability for the allocation of resources and a focus on efficiency.

### **C.A1.2      The Long-term Care system**

The Commonwealth Government funds the Medical Benefit Scheme (MBS), the public contribution to Medicare - compulsory medical insurance - and the Pharmaceutical Benefit Scheme (PBS), which is largely a subsidy to the elderly, out of tax levies.

The state/territory governments fund and run acute and chronic care hospitals with federal money and jointly (with the Commonwealth Government) fund the Home and Community Care (HACC) programme, as well as housing services.

The local government plays a role in administering or providing some services. Dual responsibility for funding community and health care leads to a wide range of different programmes and services and leads to confusion as to which services are available to whom.



## ANNEX 2: AUSTRALIA'S DEMOGRAPHIC PRESSURES

Like other countries, Australia's older population is growing, not only in absolute terms but also as a proportion of the total population. Today, around 2.2 million Australians - an eighth of the total population - are aged over 65, and 1.5 million of these are over 70. The Australian Bureau of Statistics estimates that this will double in percentage terms to 5.7 million (23%) by 2041, as a result of both an increasing life span and declining birth rates. As elsewhere, the fastest growing population group will be the oldest 'old'. The number of people aged over 85 will increase dramatically from 200,000 today to over 1 million in 50 years time - an average of 11,000 a year until 2026 and 29,000 a year between 2026 and 2041, as the baby boom generation (born between 1946 and 1965) reach advanced old age.

As in the UK, officials have concluded that the costs of Australia's aging society should be manageable. The press and public hyperbole about the aging population 'explosion' and the generation of an associated sense of crisis will be used by politicians to push through reform, although the reality will not be quite as bad. For example, the shift towards compulsory superannuation will reduce the reliance on front-line funding in the longer-term.

Although there is no demographic 'crisis', the aging of Australian society will have cost implications for the Government, community and individuals, mainly associated with ensuring people have adequate retirement incomes and access to appropriate health and long-term care facilities. Population aging is estimated to have added 0.6% a year to real health outlays over the last 20 years - around a fifth of real increase of 3.3% in total health care spending. But this needs to be seen in context - it is well below the 1.4% each accounted for by population growth and demand/expectation factors.



# A STUDY OF THE BOUNDARIES BETWEEN HEALTH AND SOCIAL CARE FOR OLDER PEOPLE IN DEVELOPED COUNTRIES

## III. COUNTRY CHAPTERS

### D. SINGAPORE

#### D1.1 Summary and Overview

##### The Big Picture

**Singapore is unique in Asia, if not the world, in combining centrally directed private saving with a strong orientation towards individual and family responsibility.** Since its independence in 1965, the technocratic Government has had an eclectic tradition of combining the best ideas from elsewhere. Combined with strong entrepot trade-fuelled economic growth, this has the benefit of allowing Singapore to benefit from technology and best-practice from other countries (eg in hospital-based medical care or telecoms infrastructure). But it also has the potential downside of promoting a confusing blend of Eastern and Western approaches. The current community care/institutional care boundary is perhaps an example of this.

The **country is now in a development and expansion phase of setting up proper community provision for the elderly and mentally ill**, although the Asian economic downturn has put the brakes on this process temporarily. Singapore's relatively small size - that of a medium-sized Australian state - allows the Government and people to address problems as they arise and representative committees to highlight needs and recommend solutions.

Overall, it is **hard not to be optimistic about Singapore's ability to conceive, finance and implement solutions to its social problems.** Although the philosophy espoused is that of providing 'appropriate and cost efficient care based on individual needs', the darkest cloud on the horizon is perhaps the continuing reliance on costly US-style high-tech hospital-based medicine and mental health treatment, which may squeeze out programmes and funding for wider social needs.

There is **good provision in Singapore for people at either end of the social scale.** For those in good health with average incomes or above, a range of private housing, medical and social facilities exist. Equally, the Government has put in place policies - Medifund and low-cost Government-funded polyclinic services, low income housing as well as employment and social support programmes - to help poor and needy Singaporeans falling beneath the Public Assistance (PA) income threshold of around S\$800 (£270) a month. For those just above the PA level - not wealthy enough or in regular enough employment to self-fund, but with sufficient income to qualify for basic welfare assistance - the shared view of those with whom I talked was that this group potentially faced the greatest problems.

## **A policy of self- and family reliance**

The aim is to provide concentric rings of care around the client/patient encompassing respectively the family, the community and, lastly, formal care organisations. The philosophy of care for the elderly and those with mental health problems follows the World Health Organisation's 'Surround With Care' model. The objective is to encourage care to be provided within the inner 'rings' (ie individual and family) and thereby keep costs down.

**Outreach, community care and case management services, as developed in Australia, Europe and the USA are still in their infancy in Singapore.** But they are now growing fast in response to changing demographic trends and perceived service shortfalls. Nearly 80% of elderly Singaporeans live with their children, families or relatives - a significantly higher proportion than in other developed countries. Partly as a result of this Asiatic family structure, Singapore's policy strongly emphasises self-help and family-centred care. Community or residual welfare net services are therefore only patchily available to prop up the family in case of need. As with the breakup of the extended family in Western society with the advent of industrialisation, this model will come under stress in coming years as society 'modernises'. Families no longer choose to live together, and the elderly seek more independence and choice.

## **Demographic trends**

**Singapore has one of the world's fastest aging profiles - the writing is on the wall for Singapore** - see Annex 1. This 'young' country (only 34 years old) also has a relatively youthful population: only 7% of the population is over 65 and nearly a quarter is under 14 years old. But this will not last long. As the current generation of baby boomers retire from 2010 onwards and historical low fertility rates (due in part to the policy of giving incentives for people to have two or less children in the 1960s) reduce future births, the population balance will swing dramatically.

## **Lessons for other countries**

**Singapore's welfare system is probably its most original feature.** The health and social care financing system relies on a mixture of compulsory savings, client co-payments, Government subsidies and a residual welfare net. The main instrument for achieving this mix of public/private provision is mandatory individual and employer contributions to the Central Provident Fund (CPF). In brief, the CPF requires every employer and employee to contribute 20% of his/her income, ie 40% of their income in all into a fund. Funds built up are then credited to a variety of accounts from which the individual can draw to purchase a home, make investments, pay medical bills and, ultimately, meet long-term care needs. This system broadly ensures that each employed individual has sufficient funds to meet their social needs, while providing basic housing for all and keeping overall health expenditure down to under 3% of GDP. The Medifund system provides a basic welfare net for health care expenses.

## **D1.2 The Strategic Framework for Delivering Long-term Care**

### **D1.2.1 The care philosophy and framework**

Except for mental health services for the elderly, there is as yet no clear detailed strategy for mental health or long term care agreed on by ministries and the voluntary welfare sector along, say, Australian lines, and no unified consensus about how care should be delivered. On the whole, ministries tend to operate with a 'medical model', ie an institutional, treatment-based approach, while the voluntary sector has a psychosocial and community-oriented perspective.

#### **The care philosophy**

The philosophy underpinning policies, programmes and services for the elderly is four-fold:

- encouraging individual responsibility for old age;
- preserving the family as the primary care giving unit;
- increasing the role of the community as the provider of support services;
- with the Government playing the traditional role of catalyst and provider of basic infrastructure services.

The overall orientation is to keep the elderly at home and in the community rather than in institutions. Singapore still has the family structure and orientation to do this, although it is increasingly recognised that social trends towards the disintegration of the family and individualisation will mean that the 'community' dimension of services will need to be strengthened.

Along with ensuring that the savings of individual Singaporeans are adequate to meet the health and social care needs of the future, the Government's main challenge will be to maintain the informal sector's willingness to shoulder the burden of care. To this end, the Government has adopted the 'Many Helping Hands' policy. But the Government has not yet got a clear picture of the aspirations of the elderly - the Ministry of Community Development (MCD) is therefore hoping to commission a further social survey to ascertain the views of ordinary Singaporeans.

#### **The policy framework**

The Singapore Government has been actively thinking about aging since the 1980s and more actively over the last 5 years. An Advisory Council on the Aged reported to the Government in January 1989 and made recommendations on attitudes towards the aged, employment and retirement age, community-based programmes and residential care. In 1995, a National Survey of Senior Citizens was carried out - building on an earlier report in 1983 - which provided information on the characteristics, needs and problems of senior citizens aged 55 and above. The National Council for Social Services stated that planning for elderly services into the

new millennium was good. Gaps in services had been identified, and policy was being reviewed in a collaborative fashion with VWOs and the NCSS.

## **Ministerial responsibilities**

Several different ministries and agencies are involved in care for the elderly:

The Ministry of Community Development (MCD) is the lead Government agency for aging matters and drives Government policy responses to the challenges of an aging population. MCD's Elderly Development Division works with various ministries - including Health, Manpower, Communications and IT - and statutory boards and bodies (National Council of Social Services, People's Association, Housing & Development Board, etc) together with other Government & non-government organisations to ensure comprehensive and coordinated programmes and services to cater to the needs of older people;

The Ministry of Health (MOH) has responsibility for deciding overall health policy and providing health care to the sick elderly (aged over 65);

the National Council for Social Services (NCSS), an umbrella body for coordinating the activities of VWOs, seeks to facilitate help for the frail elderly (aged over 60). It works with ministries, community groups, VWOs and the private sector to identify service needs, mobilise resources to meet these needs, promote volunteering and increase professionalism and accountability in the social services sector.

### **D1.2.2 The care model**

Not surprisingly, given its heritage, the fundamental British split between mainstream health services on the one hand and social services on the other is replicated in Singapore.

In response to the growing recognition of the need to develop policy and service responses for the elderly, the Ministry of Health established a Division of Elderly and Continuing Care in May 1997. Its mission is to ensure that the health needs of the elderly sick, the chronic sick, and the terminally and mentally ill are met over the next two decades and beyond. MOH's mission is to ensure that facilities, services and manpower required for continuing care of these target groups is put in place. Although it is hard to ascertain how much they are put into practice, the principles followed by MOH regarding the health care of the elderly are:

individual responsibility: the individual must take responsibility for their own care, but there is a safety net for those unable to do so;

prevention: the 'well' elderly are advised of preventive health measures and the MOH runs public health education campaigns promoting healthy living;

care in the community: the elderly should be cared for in the community.

Encouragingly, a number of health-related policy initiatives are under way. The

Ministry has started work on providing long-term care insurance. The chosen method of doing this is likely to be through a stand-alone insurance plan, rather than an expansion of Medishield to cover long-term care. Action is necessary as the CPF Special Account, which in principle covers costs arising from old age, only covers costs arising from acute health care and catastrophic events. MOH are also looking to provide more streamlined services, eg through multi-service centres.

### **D1.2.3 Long-term care funding**

Five to ten years ago, the Ministry of Health used to fund and deliver services directly. Today, responsibility for service delivery has been delegated and patients move between general hospitals, community hospitals and then into community support services. The philosophy behind health-care financing is one of individual responsibility, though, as we are to see in the mental health service, public funding is actually increasing. The Government's aim is to avoid paying *from the first dollar to the last dollar*, ie there is always an element of patient co-payment. Hence, although a subvention from the Government is the main funding source, the balance of care costs is funded by patients themselves.

There are three main methods for financing health care and controlling costs: a piece-rate subvention, which is equivalent to an amount given to hospitals, etc, on a per patient day basis;

- ii. a revenue cap, which sets a limit on the revenue care institutions can make from charges, etc, based on an average revenue per patient day. Together with the subvention, the revenue cap effectively amounts to an indirect control over hospital costs and growth;
- iii. direct funding of voluntary welfare organisations (VWOs), who mostly run health services for the elderly (see below).

The Government (MOH) provides assistance to a wide range of VWOs providing a wide spectrum of services, including counselling and befriending, a meal service, day care, domiciliary care and residential care. VWOs are heavily subsidised, which puts a brake (as now in times of economic stringency) on their development. Funding is provided through several channels:

substantial capital and current grants to VWOs. The Ministry will pay up to 90% of the capital and development cost of a new facility and 50% of recurrent spending (75% for residents who are on public assistance schemes). If the VWO is affiliated to the NCSS, as many are, it can apply for a further grant of 50% of its recurrent spending. In 1997, the Government subsidy for the furniture and equipment cost for VWO development projects was increased from 5% to 10% of the construction cost;

help with obtaining premises (waiving development charges), provide state land or allow free/low rental of State property for new facilities;

assistance in recruiting suitable foreign workers;

crucially, it also relieves pressure on VWOs through providing a basic welfare net, eg free consultation and drugs are given to people who are on public assistance at Government-funded polyclinics.

The Government is aiming to gradually move from flat rate (input) funding to piece rate (output), and then ultimately to performance-based funding (outcomes). Recently, for example, the subsidy for the operational costs of VWO-operated nursing homes was changed from a flat per capita funding regime to piece-rate funding on the basis of four disability categories. In turn, each category of nursing home has different staffing requirements, eg Category I Homes (for 'well' elderly) have a staffing ratio of 1:30 residents, while Category IV homes (for very sick elderly) have a ratio of 1 staff to 2 residents.

#### A move to case mix funding

Following the Australian example, the Singaporean Government is planning to alter the funding regime from a 'bed days' to a case mix and DRG approach. In Australia, geriatric medicine is not included in the DRG-funded system as it is classed as semi-acute, but Singapore plans to include geriatric care within the system. Given the way the DRG system is intended to operate, this may well have negative consequences for the elderly in Singapore. The elderly tend to present with a number of complaints simultaneously: under a DRG system, the treatment of each symptom would be classified, registered and billed as a separate episode of care. Besides artificially inflating activity rates, this would mean that an elderly patient would need to be readmitted, perhaps several times, to have their condition, eg stroke/eye problems, etc, properly dealt with, with resulting additional costs and poorer health outcomes.

#### Comment

Given the inexorably rising numbers of the elderly, some experts believe that without additional community facilities and examination of the appropriate funding system - including how the DRG system will work for the elderly - the current system will run into crisis when the number of elderly over 65 exceeds 10% of the population - perhaps in 5 years time. However, it is likely that before crisis occurs, sufficient money will have to be put into community facilities to avert a 'meltdown' of inpatient care. Nevertheless, a lot of the pain and worry associated with chronic illness will still continue to be borne, necessarily silently, behind closed doors.



### **D1.3 Roles and Responsibilities of Different Agencies**

There has been some effort to discuss the roles and boundaries of different agencies/professional groups, but more needs to be done to achieve greater clarity. The Government recognises that a number of policies need to be brought together to provide support to the elderly. The five key policy planks are employment, social security, social care, health care, the built environment (housing) and policies towards the voluntary sector.

#### **D1.3.1 Employment policy**

Singapore's main thrust is to encourage older workers to continue contributing to the economy for as long as possible. To this end, the recently passed Retirement Age Act outlaws dismissal of an employee who is below 62 years of age on grounds of age and states an intention to raise the official retirement age to 67 years in stages. Second, in order to increase labour force participation of the elderly, the Government is trying to remove disincentives to employing older workers by lowering barriers to flexible and part-time employment, retraining older workers and seeking to change employer attitudes about hiring older workers. Third, there is a 'Back to work' programme to help those who have left the workforce find suitable employment. Only time will tell whether increasing labour force participation of the elderly and the new phenomenon of unemployment due to the economic downturn are compatible.

#### **D1.3.2 The Central Provident Fund - Singaporean social security**

The second - and key - plank is increasing the financial security of the elderly. The primary instrument for this - and the key pillar of Singapore's social security policy - is the Central Provident Fund (CPF). This was set up in 1955 under the Central Provident Fund Act to provide financial security for workers in their retirement or when they are no longer able to work. It is administered as a Statutory Board under the Ministry of Labour. Over the years, the CPF has developed into a comprehensive social security savings scheme, which takes care of retirement, home ownership and health care needs. In September 1997, there were 2.75 million members in total, with 1.22 million currently 'active' members.

The CPF covers all employees. The monthly CPF contribution is a staggering 40% of the individual's income with employees and employers contributing 20% each. Mandatory contributions are required by the self-employed to the Medisave (Healthcare) Fund. For 1999, the employer's rate was reduced to 10% for workers under 55 in view of the Asian economic downturn. The rate of contribution is reduced progressively for members above 55 to encourage continued employment (employee/employer rates for 55-60: 12.5%/7.5%; 60-65: 7.5%/7.5%; 65+: 5%/5%). Monthly contributions are subject to a maximum of S\$1,200 each for the employer and employee, ie the maximum level of contributions is reached at a salary of S\$72,000 (around £25,000 - about the threshold for top rate tax in the UK).

CPF contributions are channelled to three accounts - the Ordinary, Medisave and Special Accounts. On reaching age 55, each member also has a Retirement Account. The bulk of the contributions (between 28% and 30%) are credited to the Ordinary Account, which can be used for housing, approved investments, insurance,

education and transfers to top up a parent's retirement account. A further 6% to 8% is credited to an individuals' personal Medisave Account, which has a limit of S\$20,000 to prevent unnecessary use of medical services and can be used for:

- hospitalisation expenses (including community hospitals);
- attendance at approved day rehabilitation services;
- approved medical expenses; and
- approved medical insurance premiums.

A further insurance-type scheme - Medishield - and Medifund provide additional cover. Medishield is voluntary and covers costs associated with catastrophic illness such as acute health care costs and dialysis. Incomeshield, a trade union administered fund, is an enhanced version of Medishield. Medifund is the safety net medical cover for poor Singaporeans, and is funded by the Government through a budgetary contribution to an endowment fund. The interest from this fund is used to pay for the care of individuals with little or no income.

Finally, 4% of an individual's income is credited to the Special Account, which can be used for old age and contingency needs. Withdrawals from the CPF Accounts can be made at age 55 and every 3 years thereafter. Under the CPF Act, on reaching age 55, members have to set aside a minimum sum in their Retirement Account (S\$55,000 in 1998-99 and rising by S\$5,000 a year to reach S\$80,000 in 2003). Only S\$12,000 of this sum needs to be in cash - the rest can be in property. CPF members who are unable to meet the minimum sum requirement at 55 can have their accounts topped up by their children. From the national retirement age (currently 60, but due to rise to 67), members receive a monthly income from the retirement account. Alternatively, the sum can be deposited with a bank or used to purchase an annuity.

### **D1.3.3 Social policy**

The Ministry of Community Development (MCD) develops and promotes social care programmes and services for the elderly, while MOH funded voluntary welfare organisations (see paragraph [31]) provide a range of community-based elderly services. MCD-funded services include 7 Social Day Centres, currently providing 405 places; 20 Senior Activity Centres (SACs) serving 25 Housing Development Board (HDB) blocks of flats housing over 2,200 elderly households, and a befriender service - essentially a good neighbour programme - with 1,200 volunteers serving 2,000 elderly persons.

The SACs are part of MDB-HDB projects to upgrade the living environments in one-room HDB rental flats to make them more user-friendly for older persons. The HDB blocks are served by VWOs which set up SACs at the foot of the blocks (see section on Thye Hua Kwan Moral Society in Best Practice section at the end of the chapter). The SACs provide and facilitate community-based care and support services for the older persons in the block, as well as in the neighbourhood.

The Ministry of Community Development is also developing much-needed sheltered homes for the low-income elderly providing both housing and the support services to enable the elderly to maintain their independence within the community. Currently,

19 homes run by VWOs exist, providing 678 places. The problem is that as clients age and become more frail, the set up in these homes can no longer cope with their needs and there are insufficient places in nursing homes to cater for them. One possible solution might be to introduce home care services into the sheltered homes making them more like the American Assisted Living concept. But even this has drawbacks (see US chapter).

The needs of day centre clients and their clients have undergone important changes in recent years. The growing numbers of the elderly, the dissipation of the extended family and growing participation of women in the work force has meant that the existing configuration of services is no longer adequate to meet the needs of the elderly and their families. One clear indication that this is the case is the rising demand for daycare services by families of people with moderate/mild frailty and disability. In particular, families with young children, families with people away working, families with poor life skills, or people who are elderly themselves and caring for the very old are likely to increase their demands on social services.

#### **D1.3.4 Health care**

There is a dual system of health care delivery: 80% of primary care is given through private GPs and 20% through Government polyclinics; these percentages are reversed for hospital care. The Government's overall approach is to keep the elderly as independent as possible so that they can live as integral members of the community. The Ministry's main policy concern, unsurprisingly, is how to contain the burgeoning costs of health care for an aging population the pace of which has recently accelerated.

The process of discharge to a publicly-subsidised nursing home is as follows: when an elderly person is discharged from hospital, they are assigned to the MOH-run Care Liaison Service (CLS) to arrange a transfer to a VWO-run home. (NB If someone requests private nursing home care, the family will proceed to make their own arrangements.) Referrals from the hospital for publicly subsidised care are usually initiated by the doctor (unless relatives, etc, request a discharge), which ensures a 'medical or nursing' reason for the referral.

The hospital medical social worker processes the application, interviews the family to decide if they 'qualify' for a VWO subsidised home, assesses eligibility for free polyclinic services based on family income and circumstances and explores other care avenues (home care, day care, etc). Once the screening has been done (the nursing home assessment form is based on an Australian model), an application is sent to the CLS, who refer clients to nursing homes based on their level of needs.

MOH have embarked on a care home building programme and are convinced that there will be an adequate number of beds in nursing homes, to meet an assessed shortfall in this area, by the year 2003. Although the Government is now aware that home care services urgently need to be developed to assist the homebound elderly, there is still a detectable institutional policy orientation that runs counter to that now being pursued in most of the developed world.

MOH have a key role in helping VWOs to develop services - and in this respect

resemble UK local authority Development Departments, or perhaps health authorities, who oversee local provision of services. The Ministry has a wide-ranging role: from conducting financial audits to providing help with building costs (at around S\$50,000 per bed or S\$1,200-1,600 per square metre) and repair and maintenance costs for care homes.

The NCSS's role is to then identify service gaps. There are four networking committees under the NCSS, which serve as a forum for service providers to voice their opinions. Three previous coordinating committees for geriatric care were merged into one National Geriatric Coordinating Committee. This committee brings together hospital managers, geriatricians and psychiatrists, as well as LTC and VWO representatives. It also advises the Ministry on the development and distribution of services and facilities for the elderly, to set standards of care and define care protocols for elderly services and to promote coordination and continuity of care for the elderly in Singapore.

Besides the usual range of ministry duties (public health monitoring and screening, planning medical manpower requirements and population planning, etc), the Ministry of Health (MOH) provides acute care services and oversees residential and community-based services for the elderly that are medical in nature or have an active rehabilitative component. It also sets financial subsidy levels for VWOs. Services sponsored by the MOH include:

- 17 VWO-run day rehabilitation centres, providing about 600 day care places for the elderly and frail;
- 3 day care centres provide 100 day care places for the elderly with dementia;
- 4 community hospitals, providing 426 beds;
- 6 VWOs provide domiciliary, nursing and medical services;
- over 4,700 nursing home beds provided by 47 homes - split equally between voluntary sector nursing homes and commercial homes;
- a care liaison service which coordinates and facilitates the placement of the elderly sick into appropriate residential or community-based medical/nursing care facilities. In 1997, most applications were placed in residential homes.

Probably the main contribution that MOH makes to care for the elderly is through the administration and service provision funded through the Medisave, Medishield (and other licensed insurance schemes) and Medifund schemes (see paragraphs 19-23 under social security above).

### **D1.3.5 Housing**

In Singapore, nearly 80% of elderly persons live with their children, families or relatives. The Government encourages the elderly to live with or close to their families. The Housing Development Board (HDB) is in the process of building Studio Apartments for the Elderly - the first of which will be completed by year 2000. While these are smaller than other HDB flats, they will be equipped with elderly friendly features such as alert / alarm systems. An elderly couple who own a public (HDB) flat can sell the existing flat to purchase a studio apartment and use the balance to top up Medisave and purchase an annuity. Space will be allocated for social and communal facilities run by VWOs and commercial enterprises.

In addition, since 1993, MCD and HDB have jointly implemented a project to improve the living conditions of the low-income elderly living alone in 1-bedroom HDB rental flats. The Government has financed the refurbishment of rental blocks with high concentrations of the elderly, providing an emergency alert system, lift landings on every floor, handrails and ramps. MCD funded Senior Activity Centres will provide support services and serve as points of contact in times of crisis. The Government is working on Revisions to the Building Code Regulations and the Code on Barrier-free Accessibility in Buildings to improve disabled access to buildings. Measures to make the public transport system more elderly- and disabled-friendly are also being planned.

## **D1.4 Delivery of Services and Accountability Mechanisms**

### **D1.4.1 Delivery of care services**

Recognising that aging is a cross-government issue, the Government has recently set up an Inter-Ministerial Committee (IMC) on the Ageing Population to identify the challenges posed by the rapidly aging population and develop policy directions and lead inter-Ministry attempts to address these challenges. This committee was formed in October 1998 and has a slightly unusual structure. It is chaired by a relatively neutral minister in policy terms (Minister for National Development) but has the key players - MCD and Health Ministers - as deputy-Chairmen. The IMC has broad membership with representatives from relevant ministries, statutory boards (eg NCSS) and bodies (see paragraph 14 for examples) and non-Government agencies. The Committee is due to report by the end of 1999.

#### Problems with this arrangement

There are two main problems with this policy framework. Firstly, despite the Inter-Ministerial Committee there is insufficient policy and service coordination. Services are generally funded by the sponsoring department, with little coordination with or shared financial input from other policy players. For example, health and social care funding is distributed down two different channels and therefore co-located senior day centres and rehabilitation centres cannot receive one funding stream but are separately funded, run and monitored.

The second problem is that the facilities that currently exist are not adequate to cope with the demand. Admirably, the Community Care Networks (see Best Practice Example 1 below) have been commissioned to report on service gaps. The reports are a salutary read and document gaps in services at all levels and dimensions, including the adequacy, coordination and integration, accessibility and quality of services. The Service Gap reports note that current services do not provide for aging in place and therefore dependent and frail elderly face a severe shortage of community services. Problems include:

- no integrated planning blueprint for community service provision;

- a resulting lack of coordination among service providers and collaboration between service providers, policymakers and the private sector;

- although there is a wide spectrum of types of services, in many cases these only cater for a small number of clients;

- many services are not locality based. But transport and escort services are severely lacking, which deprives people of access to services;

- as elsewhere in the world, with a labour intensive service facing financial stringency, many services face chronic staff shortages;

- the staff that are employed need more training and upgrading of expertise to provide better quality services;

there is no system for the regulation of standards of practice among services.

#### **D1.4.2 Regulation and accountability**

Regulation of the non-residential sector has been patchy. However, there is some progress. The Private Hospitals and Medical Clinics Act and Regulation, which regulates residential long-term care services, covers non-residential services, too. In addition, the Ministry sets guidelines on staffing and space norms, etc, to ensure minimum standards of care. The Community Care Network advocates self-regulation and, to this end, has submitted a set of standards for day care centres to the MCD's Committee on the Aged. The MCD included these standards in a 'Guideline on Standards of Care for Community Based Elderly Services', launched in April 1998.

## **D1.5 Broad Policy Debates**

The main policy concern, not surprisingly, is how to contain the likely fast-rising costs of health and social care for an aging population: the numbers aged over 65 will triple between now and 2030. The Government's policy framework and responses to this issue are covered in Section 1. Other policy and service delivery issues currently being debated include the following:

### **D1.5.1 The role of the family in elderly care**

The role of the family is not so much of a debate - there is broad consensus at the moment in Singapore that families should take care of individuals who cannot care for themselves - but more of a distinctive feature of Singapore's social constitution. Only 15,000 elderly people over 60 years (6% of total) live on their own in Singapore at the moment. This is mainly by choice, but there is also a concerted Government effort to keep parents and children together. Measures taken by the Government to encourage co-location include:

- tax relief for parental assistance. Children living with their parents are entitled to parents' tax relief of \$3,500 for maintenance of the parent. Clearly, this is only useful if the family pays sufficient tax;

- a CPF Housing Grant Scheme, which encourages married children to live close to their parents;

- various schemes to encourage extended family living;

- Medisave monies can be withdrawn to pay for parental care directly or used to pay Medishield contributions;

- the Maintenance of Parents Act (1995) provides a legal channel for parents who are aged 60 and over and who are unable to maintain themselves to apply for an order that 1 or more of his/her children give them a monthly allowance, a periodical payment or lump sum for their maintenance.

But the Government is aware that, in future, more elderly will prefer to live on their own and more young families might also want to live separately from their parents. The Government is therefore looking into widening the choice of housing options for the elderly.

### **D1.5.2 Adequacy of provision for the nearly poor**

In Singapore, medical care is acute- and institution-focused. For the well-off, the CPF and insurance provisions will almost certainly ensure that care needs are met and, if necessary, personal funds can be used to employ a maid, private nurses and ambulances to provide care in the home. At the other end of the scale for those on public assistance (PA), care is met at public expense. While the PA level itself amounts to a bare subsistence income, at least hospital, other medical and community services are provided free.



The real problem is for those who fall in between the realms of affluence and public assistance. For the less well-off, who have very low incomes but do not qualify for (or chose not to receive) public assistance, they either receive poor or no care at home or end up overstaying in hospital. The problem is therefore hidden, with old people left dying at home from avoidable conditions such as pneumonia.

### **D1.5.3 Care coordination**

One issue that came up during the visits is the existing unclear and probably illogical borderline between the Ministry of Health (MOH) and the Ministry of Community Development (MCD) regarding the funding and provision of rehabilitation services. At the moment, the MCD funds social day centres, who among other tasks perform some 'maintenance' rehabilitation. But the MOH also funds organisations for 'active' rehabilitation on medical grounds. In some cases, the same organisation is receiving funding from both ministries to perform the same function.

It seems likely that it would be more efficient to have some sort of pooled funding for rehabilitation. Indeed, the Government plans that, in future, active and maintenance rehabilitation services would be co-located in one-stop multi-service centres. VWOs would then receive funding from only one ministry for their respective projects. At the time of writing, this has not happened. But VWOs point out that there are also a number of other issues that also need to be resolved before genuinely coordinated services can be said to be available:

- the need for a user-friendly funding system for providers, including clearer guidelines on how the Government will fund, for example, nursing home beds;

- there is still too little coordination between home medical, home nursing and home help services, where the latter are available at all;

- the lack of elderly/geriatric expertise in the community, ie trained GPs and other health and social work professionals;

- the absence in many areas of carer support services.

Perhaps the most acute service gaps are in the provision of home care services and in rehabilitation and respite beds. As the Western Community Care Network Gap report notes: "Ideally an elderly person should be encouraged to remain at home as long as possible. At home the elderly can maintain social ties and involvement with family and friends. But to keep the elderly, sick and frail at home as long as possible, a comprehensive and well-coordinated home care delivery system must be in place."

The reality is different: there is a fledgling Home Care Service with service providers targeting different areas of service. As a result, there is a tremendous shortage of services, particularly for the homebound, the frail elderly without access to day care services and families unable to provide adequate care, eg for a highly dependent relative awaiting nursing home placement. Present services are also not comprehensive enough, which leads to a high number of re-admissions to acute hospitals and an increased demand for nursing home places.

A wider problem is that there is an overall lack of geriatricians and nurses trained in elderly care. As a result, VWOs do not have the expertise to provide services to the elderly, which they know are needed. There is insufficient communication with hospitals at the point of discharge - service providers are not told what services are needed and when - and communication among service providers at referral and discharge urgently needs to be improved.

There is a severe shortfall in facilities, such as community hospitals, that allow the elderly to have a period of convalescence and rehabilitation. The Ministry estimates that there is a shortfall of 381 community-hospital and 21 chronic-sick hospital beds in 1999. The shortage of rehabilitation beds knocks onto respite care facilities: there are no designated respite beds, because these beds are taken up by the shortage of rehabilitation beds. The Ministry is providing another 362 community hospital beds and 88 chronic sick beds by 2003, and estimates that, by then, there will just be a shortfall of 38 beds. Whether this turns out to be the case will depend on the volume of demand for care that hospitals and community facilities will face and whether the planned increase in home care services materialises. There must be some scepticism that the bed shortage problem will go away entirely.

#### **D1.5.4 Demographic issues and labour shortages**

At the moment, there is a shortage of labour in the caring professions, ie for work in psychiatric care, community service organisations, respite care, etc. Instead of wanting to work in mainly manual nursing and care jobs, younger Singaporeans aspire to have white-collar work and earn salaries that will enable them to employ domestic help. The Government are already actively involved in recruiting non-Singaporeans to work in Singapore and already waives the foreign worker levy (S\$350 per month per recruit) for VWOs.

But labour shortage is likely to become an increasing problem with the changing demographic profile of Singapore's population and the growing desire of the elderly to live independently. As the population pyramid 'fattens' at the top, the demand for carers is sure to increase. One answer might be to attract more unskilled 'domestic help' type labour from other (poorer) Asian countries. However, as the population ages, the numbers of people with severe conditions requiring intensive and/or skilled care, eg dementia, will increase rapidly. It is unlikely that the kind of medical and rehab care that these elderly people will need can be satisfactorily provided by domestic helpers, however hard they are willing to work.

## **D1.6 Best Practice Examples**

### **Example 1: The Community Care Network**

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Like all good innovations, the idea for a network did not come from a single source. The Ministry of Health formed a coordinating committee for elderly care services in 1994, with representation from Voluntary Welfare Organisations (VWOs) involved in day care, nursing homes and other community providers, and hospital managers and the Ministry of Health. This was initially chaired by the Ministry of Health and then by the Head of Geriatric Medicine at Alexandra Hospital - one of the centres for geriatric care. The aim was to explore roles, problems and facilitate inter-agency referral and collaboration in each of the 3 zones for elderly services - East, West and Central. The focus was on looking at patient flows from hospital to (for example) day centres and back to hospital again.

Separately, the Singapore National Council for Social Services (NCSS) had also identified the fragmentation and duplication in service provision as one of the main hindrances in the effective provision of community-based services. To get better coordination of elderly services, NCSS set up several networks, mainly comprised of service providers, in each of the 3 elderly service zones (E, W and C).

Inevitably, the Community Care Network duplicated some of the people from the Health Ministry's network, but had representation from MCD and excluded nursing home representatives. A national nursing homes network was also set up to bring together nursing home operators to share experiences, discuss issues of common interest and bring about more uniformity in structure and services. Concern about duplication of services led to the merging of the three previous committees for geriatric care into one National Geriatric Coordinating Committee. The four networking committees (3 regional and one for nursing homes) continued as people felt they were a useful forum to voice their opinions and solve common problems. The objectives of the Networks are:

to address the issue of service fragmentation by promoting and facilitating networking and coordination among the service agencies;

to identify current barriers to service utilisation and ways of reducing these barriers, thereby making services more accessible to the elderly;

to identify service gaps and facilitate the development of new services;

to assist elderly in need, who would otherwise be referred to institutional homes, in the use of community-based services that would enable them to live at home and remain a part of the community; and

to enhance awareness of the concerns of the elderly living within a particular geographical region.

A couple of useful concrete outputs of the network were a common referral form and one information brochure which could be used by all community-based organisations. The work of the Western region on service gaps is particularly interesting. A useful report has been produced (Report of Service Gap's Work Group, Community Care Network (West), NCSS Elderly Services Department, 1998) which can be drawn on by policy planners in MCD, MOH and MITA (Ministry of Information). In drawing up its report, the work group drew up an inventory of existing services, assessed the adequacy and accessibility of present services and highlighted the need for new services.

Most relevantly for this study, the work group developed ideas about an integrated approach towards provision of care for the elderly. They believe, rightly, that an integrated service approach needs to involve policymakers, implementing bodies, funding and community groups, the private service sector, members of the public, the elderly and their families. The shared goal is to "create a safe and sustaining environment so that the elderly can continue to stay in the community as they age". The group drew up a framework for identifying service gaps looking at various aspects of services (coordination, adequacy, accessibility, quality and collaboration), formulated recommendations for overcoming these gaps and provided some real case examples of failures to coordinate services for clients.

## **Example 2: Thye Hua Kwan Moral Society**

Contact through: National Council of Social Services

The Thye Hua Kwan Moral Society is a community care provider to poor Singaporeans. It was formed in 1978 and has among its objectives promoting "family values and virtues". Their interest in this context lies in their provision of ground level welfare projects and services. In addition to an emergency relief fund and making cash donations, the society runs the following services:

- a free clinic, based on ground floor of an HDB block, dispensing western medicine and medical services;

- a scheme, 'Project Sunshine', which pays the monthly rental to the HDB for 60 poor families recommended by the MCD or welfare agencies;

- two Family Services Centres which provide, inter alia, counselling, information and referral, before & after school care, a senior citizens drop-in centre, free lunch, karaoke, handicraft activities and free tuition classes;

- a Child Care Centre for 80 children;

- several Senior Activity Centres, set up in 1994 and 1995, which help the elderly in HDB housing facilities.

### **Example 3: The Tsao Foundation - Hua Mei Mobile Clinic**

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This is one of the very few organisations in Singapore providing home care and case management services to elderly people. The Hua Mei Mobile Service and Clinic began as a domiciliary medical care service for the housebound elderly started in 1993/94. This involved a doctor, nurse and social worker visiting the elderly at home, doing a care needs assessment and then looking for services. The clinic occupies rent-free space on the same campus as the hospital's geriatric service and acts as the hospital's geriatric service's community 'arm'.

The Clinic now provides ongoing medical care and follow-up for their housebound patients, as well as needs assessment. Patients are managed by the medical team with a geriatrically-focused primary care team. People are put in touch with available community services. However, the problem is that available services often do not meet the needs of patients. For example, there is a lack of transport services, operating hours of day care services do not suit patients and relatives and there are inconsistent and inadequate respite services for stressed care givers. As noted in the report itself, when there are services in the community, there are often problems in trying to integrate them with hospital-based services.

The Tsao Foundation also works at a policy level to improve services on the ground. Through its work with the Western Community Care Network (see above) and, alongside the Singapore Action Group of Elders and the Gerontological Society of Singapore (whose role is to highlight elderly issues), it has discussions and makes representations to the Ministry of Health on issues facing the elderly. In turn, through the Ministry, these views are passed on to the Inter-Ministerial Committee. Some of the key issues being raised and discussed with the Ministry include families having problems looking after dementia patients at home; the lack of a user-friendly funding system for providers and the best means to provide home-based care.

## **ANNEX 1: DEMOGRAPHIC TRENDS**

Singapore has experienced rapid fertility decline and improvements in mortality rates over the past three decades resulting in a demographic profile in the late 1990s that resembles that of a developed country. The median age of the population has risen steadily since Singapore's independence in 1965, and the challenge of an aging population now looms large.

Singapore has the second fastest aging population profile - only second to Japan, although at the moment it still has a relatively young population and it will not be for another ten years that the proportions of the elderly will start growing rapidly. In 1997, out of a total resident population of 3.1 million only 10% were over 60 years of age and 7% over 65. But by the year 2030, the elderly population is expected to nearly triple - rising from present levels of around 300,000 to over 1 million persons. Over a quarter of the population will be over 60 and 19% over 65. The future is indicated by Japan, which *already* has over 16% of its population over 65. This is due to rise into the high 20s per cent by 2030 and a staggering third of its population in 2050.

The Singapore Government has been aware of the implications of its aging population for some time and actively considering the options for dealing with this challenge since 1982. One positive factor is that the state of health in Singapore is good by international standards - with a relatively low infant mortality of 3.8/1,000 live births and average life expectancy of 77 years. The causes of morbidity and mortality include the usual Western diseases (cancer, CHD, strokes, diabetes, etc) and cancer and cardiovascular disease account for 63% of deaths.

As elsewhere - for example its relatively-near neighbour Australia - in the coming years, a key plank of the Government's policy response is to improve the health and well-being of older people by encouraging older people to remain economically active, to plan properly for their years of retirement and to extend their contribution to family and community life. Nevertheless, the rapid aging of Singaporean society will have cost implications for the Government, community and individuals, mainly associated with ensuring people have adequate retirement incomes and access to appropriate community-based health and long-term care facilities.





# **A STUDY OF THE BOUNDARIES BETWEEN HEALTH AND SOCIAL CARE FOR OLDER PEOPLE IN DEVELOPED COUNTRIES**

## **III. COUNTRY CHAPTERS**

### **E. THE NETHERLANDS**

#### **E1.1 Summary and Overview**

##### **The Big Picture**

Care for older people in the Netherlands is still firmly rooted in a universalist welfare state tradition. With a population of around 15 million people, the Dutch spend around 10% of their GDP on health care. But about one-third of health expenditure is accounted for by the elderly, who make up only one-eighth of the population.

The Dutch have the highest proportion of their elderly population in residential care of any OECD country, and between 50 and 75% of older people identified as in need of care benefit from publicly funded care. The use of long-term care is therefore high by international standards, resembling the situation in Scandinavian welfare states.

Dutch society has succeeded in maintaining relatively high levels of long-term care provision, well targeted to social groups most in need of support. There is some rationing of care, especially in particular localities, but the system as a whole does not appear to be under excessive pressure. But, unlike in the UK, bed blocking does not appear to be much of a problem (though opinion is somewhat divided here), and there is no social care/NHS divide.

Instead, the Dutch have rigidities stemming from separate service delivery and funding regimes for domiciliary care, residential and nursing care and unhelpful boundaries between local and regional authorities.

Two main features of the Dutch long-term care landscape stand out:

- strong societal acceptance of publicly funded long-term care within a social insurance model, which gives an aura of stability to the current system;

- but this tendency to rationalise the existing institutional care pattern does not satisfactorily take into account changing societal expectations, the widely different circumstances of individual clients and an increasing demand for greater flexibility in care services and care delivery methods in order to respond to the diversity in chronic health problems and disabilities.

Budgets for long-term care are set at national level, but local and regional services are funded differently. This engenders one of the key debates in the Netherlands - namely whether the Government should dissolve the administrative/funding boundaries between home and residential care agencies and set up a regional fund to stimulate better coordination of care by funding care for individuals regardless of their precise care setting. Another interesting debate concerns whether the system of cash allowances should be expanded.

## **Future trends**

Future trends are therefore likely to include:

**more decentralisation of the planning** of long-term care. Against the background of a greater emphasis on 'managed care' and performance management, there is likely to be greater flexibility in service delivery;

**more integrated provision** of long-term care. The number of integrated organisations which provide differentiated packages of care with institutional and community-based components, is likely to grow;

**greater client empowerment**, including the possibility of developing personal budgets and care allowances into a system of 'vouchers' which can be exchanged with certified service providers;

a **greater 'welfare pluralism'**. This might involve more widespread means-testing and an increase in private markets for long-term care, perhaps through an extension of private care insurance schemes with tax privileges, and more restricted eligibility for publicly funded long-term care.

## **Interesting lessons**

Interesting lessons, which are also worth following, include:

the **innovative and creative work of housing associations**, who have separated the housing and service elements of care while blending both elements into a high quality overall package of care - see De Woonplaats and Humanitas examples in the Best Practice section;

Dutch **experiments with 'trans-mural' care** (see paragraph 53).

## **E1.2 The Strategic Framework**

### **1.2.1 The philosophy of care**

Long-term care in the Netherlands can be characterised in terms of 'stability and diversity' within the context of a universalist welfare state tradition. Long-term care is centrally controlled and publicly funded, with relatively high service levels - and hence expenditure - as an accepted outcome.

There is a health insurance system, mainly to cover episodes of acute illness plus compulsory exceptional needs insurance and solidarity payments. The latter covers risks that are not easily, if at all, insurable in the private market, eg long-term home care, stays in residential or nursing homes, care for the handicapped and psychiatric care. The National Council for Illness Fund controls the budget for 'exceptional illness' - around 20 billion guilders (about £7 billion) in 1996.

The premiums for the exceptional illness Fund are compulsory and are, not surprisingly, an important political issue. A couple with 3 children might pay around 680 guilders (£230) per month for health insurance of which about 200 guilders (£65) per month will be accounted for by the exceptional illness and solidarity contributions.

Although there does not seem to be a strong feeling that the system is excessively costly, the existing structure is under attack from two different angles:

policymakers believe that the system needs to be made more accountable and mechanisms for promoting efficiency need to be underscored;

care recipients argue for more flexibility in the composition of care and more freedom of choice in the selection of providers.

Care systems for the elderly are currently embedded in regional structures, which the Government wants to decentralise to a local level. The system is also still relatively institutional: for every 1,000 people over 75, roughly 20% are in residential care and 20% are receiving some form of home-based care.

### **1.2.2 The policy framework**

Health and social care in the Netherlands is characterised as a 'public contract' model. The Dutch Government regulates the supply of health and social services, predominantly by setting budget allocations and by directing funds to particular service and geographical areas. Private non-profit organisations provide the vast majority of services within a framework of quality standards laid down centrally or by health insurance companies. These organisations control the way services are allocated. The distinction between health and social care or welfare services has become less marked with home nursing, home help and institutional care seen as equal components of the regulatory and financial framework.

There are four main strands of policy strategy and development:

a clarification of the roles of hospitals and social care organisations, ie the boundary between 'cure' and 'care';

engendering a greater differentiation in long-term care services. New provisions have emerged such as short-term stay places, day care facilities, intensified home care;

instituting incentive schemes for informal care givers, eg personal care allowances;

developing programmes of sheltered housing in conjunction with social housing and existing institutional care organisations.

### **E1.3 Roles and Responsibilities of Different Agencies**

The AWBZ legislation underpinning services for the elderly set up a Long-term Care Health Board whose job it is to oversee services for the elderly, disabled and mentally ill. At the moment, management and delivery structures are divided into care types, eg home care, residential homes, nursing homes, etc - with agencies at regional level delivering care in each care setting. The Dutch are discussing whether they should dissolve the boundaries between care agencies in different settings and institute a multi-setting regional fund.

So, while care services are provided at a regional level, housing and welfare services are largely the responsibility of local government. Local government is responsible for accommodation in people's own homes, housing (including accessibility and quality of social rented sector), the provision of technical aids, eg wheelchairs and adaptations in the home, and - as in the UK - welfare services.

There are 31 Regional Health Authorities, covering around 500,000 each (similar to the UK) and 400 local authorities. Local and regional authorities share responsibility for care of the elderly, although as we've already seen, they are separately funded.

One of the most encouraging developments is the growing collaboration between local health authorities and integrated care enterprises. Since local public sheltered housing is better and cheaper than residential or nursing homes, an improvement in the care environment can occur if domiciliary care agencies were able to build alliances with housing corporations.

### **E1.4 Financing Arrangements and Accountability Mechanisms**

Health care in the Netherlands is financed through a system of health insurance and taxation with a sharp distinction between 'cure' and 'care'. For a large part (around two-thirds) of the population - ie employees with incomes below a certain level, recipients of social security payments and pensioners admitted to the scheme prior to reaching 65 years of age - the costs of primary care and hospital services are met through mandatory contributions by employees and employers to a social insurance

fund. Those with higher incomes take out private health insurance schemes; there is also a special arrangement for civil servants.

The Dutch have 'socialised' the costs of meeting long-term care needs. Long-term care costs are paid out through a specific national care fund set up under the General Act on Exceptional Medical Expenses (AWBZ). Within fixed spending limits, this fund covers the planned supply and the needs-tested use of services for the chronically ill, the elderly, the physically disabled and those with severe learning disabilities and those with severe psychiatric disorders. The national care fund is financed through taxation from all citizens with the Government topping up the fund if necessary.

At a national level, budgets are fixed for home care, residential care and nursing homes. This inevitably means that, with relatively stable pricing structures, funding volumes determine the volume of places - currently around 120,000 places (costing around 40,000 guilders a year) in residential care homes and 60,000 nursing home beds (costing around 90,000 guilders a year) across the country. Strict means-testing for the receipt of home helps on a national basis means that it is difficult for higher income people to get access to a publicly funded home help.

One perversity of the incentives in the system is that to improve care, it is important for local authorities to provide back-up services such as domestic alert/alarm systems and social day care facilities. But it is irrational for them to do this, as it will cost them money and yield savings (from reduced nursing and residential care costs) to regional health authorities.

### **E1.5 Service Delivery Models**

Most health care regions have successfully built appropriate referral systems from medical (hospital) settings to social settings (home, residential and nursing homes). A hospital discharge team assesses people for specialist nursing care.

As in other countries, acute hospitals have reduced their average lengths of stay and concentrated on their core function of providing a 'cure'. As a result, bed blocking is not seen to be a significant problem - accounting for under 5% of hospital bed days.

The process of assessments for long-term care is not unlike that in the UK. Assessments are done separately for mental health and handicapped clients and are performed by regional assessment teams on the basis of objective criteria in the form of assessment protocols. Assessors work with administrators from the exceptional illness fund and with local government for aids and equipment. Cases are usually agreed locally by assessors and care managers without reference to other parties. The law states that the care provided must be both adequate and the cheapest available.

Although assessors take the available funds into account in deciding who to recommend for long-term care, they cannot commit funds as (like the German system) the budget is held by service providers on behalf of the AWBZ. Hence the Dutch are somewhere between the Australian rigid separation of needs assessment, funding and care management and an unseparated system.

### The Regional Assessment Team

As from January 1997, every local authority in the Netherlands had to set up a regional assessment team (RAT) - we visited the team in Arnhem. The team is multidisciplinary - comprising one person from the local authority, one from an insurance company, one representative from a care centre, a user representative and an administrative secretary. All worked for the Arnhem local authority, though usually an RAT is sited in an independent centre or foundation.

The head of the team is usually a doctor, though in theory they are selected on the basis of their management competence. The assessment usually takes place in the setting where the older person is living and is based on a telephone call or form received from the nursing or residential care home. Statutorily, the assessment must be done within 6 weeks but is often done within a couple of weeks. The recommendations made about the care plan and any necessary aids or adaptations to the person's home are sent to the care providing organisation.

The team looks first at whether they can provide care in someone's own home. If this is not possible for reasons of disability or lack of appropriate informal care, then a place in a 'home' is recommended. Out of the 45,000 applications for care received in a year, around half were recommended for care at home and half for care in a home.

As in the UK, where care is available free (or cheaply) at the point of use, the RAT operates a rationing system as there are not enough places locally for all those who want one. In this case, Arnhem RAT has a waiting list of around 200 people. They admitted that some people would probably never get into a home, though they were put on a list to pacify them. The Government had an aim that people should wait between 3 to 6 months for a place. In reality, people were waiting 1 to 3 years and so were forced to manage at home.

## **E1.6 Broad Policy Debates**

### **1.6.1 Care coordination**

As in other countries, the Dutch system of long-term care has been criticised for a lack of care coordination. Three sorts of problems have been identified:

an incoherence within Government. Poor collaboration in the planning and financing of interdependent provisions by different Government departments is thought to block the emergence of more efficient care arrangements;

a lack of dialogue and joint working by local or regional networks of service providers. This hampers the development of joint programmes targeted at clients with complex or multiple problems;

at the level of clients, a lack of coordination manifests in people who are not receiving the 'right' services, eg bed blockers or people inappropriately placed in institutional care and people with multiple problems who are not receiving the right or relevant combinations of services.

There is also the problem of the strong and unchallenged position of established service providers in the care market. The established agencies have come under severe criticism from advocacy organisations, hospital managers and health insurance companies, etc, for being uncoordinated, inefficient and unsympathetic to client needs. Detached from competition, the regular providers receive a yearly budget from the national care fund in return for delivering contracted standards in home care, nursing homes, residential homes and intermediary care.

Home care, in particular, has developed a monopolistic structure as an intended consequence of the Dutch Government's desire to reward economies of scale. A health care region of around 500,000 people - roughly the same size as the UK - will have, at most, only a few certified home care agencies, which provide nearly all professional home help and home nursing.

Dutch social research (eg by Jan Coolen, Netherlands Institute of Care and Welfare) has shown that local and regional coordination is in general rather ad hoc, being based on informal communication and temporary opportunistic alliances. Coordination by care workers has also been shown to be, on average, better developed than coordination at managerial levels although the latter is vital for developing cross-boundary working. Care networks are also segmented, with care services and housing operating under different strategies and managed by different bureaucracies. Professionals tend to work in their own bureaucracies with their own rules.

Two distinct pressures are stimulating domiciliary or home-based care: new funding regimes for home-based care for existing residential care providers and collaboration between new housing providers and care agencies. In the former case, for people with a high level of needs according to the needs-assessment, a nursing home can provide an intensive home care package. Increases in nursing home funding have been earmarked for such uses.

Dutch central and local governments are aiming at more coherence in service provision for the disabled and chronically ill (see paras [43-49]). In addition to the introduction of care allowances (see paras [30-35]), two other sets of initiatives are underway:

new coordination mechanisms are being introduced in delivery systems - including integrated care assessment/needs testing, case management and monitoring procedures;

through a number of policy experiments, new regional network organisations have been set up who are authorised to undertake a wide range of tasks, eg planning services, allocating resources and regulating service delivery.

Research indicates that these experiments improved the quality of care received by people and helped to match the demand and supply of care, but did little to improve the efficiency with which care was provided.

The Government has also aimed to direct new types of care services towards the elderly who would otherwise have gone into institutional care because of existing disabilities, serious health problems and weak informal support. But, unfortunately, it is younger more active clients who have taken advantage of these care options rather than the envisaged (severely disabled) client group. A further serious service problem is that the existing capacity of home helps and home nurses has already been reached and helpers are exhausted.

### **1.6.2 Cash payments in lieu of care**

After some years of debate, the introduction of personal care allowances was trialled from 1993 to 1995. As a result of the enthusiastic response from individuals who participated in the trials, the Dutch Government passed a national regulation on care allowances [Ziekensfondraat ] in 1995. The average budget per client is about Dfl 1,500 per month (£500 a month). Most clients (over 50%) used the budget for some kind of home help, 14% used the money for personal care or nursing services and the rest put the allowance towards a combination of services. Over a third of clients used the money to pay informal care givers or housekeepers. In 1998 around 5,500 people were allocated a personal budget and the aggregate budget amounted to Dfl 130 million - 4% of total resources available for home care.

The specification of the scheme is as follows:

care allowances can be allocated to "persons in need of home nursing and/or home help services" *if and when* the necessary care is expected to last longer than three months and the clients will continue to live at home;

the care allowance can be applied to professional help from regular home care agencies or new providers. It can also be used for contracting and paying informal care givers;

eligibility is determined through a process of needs testing, taking into account



the services which can be provided by the clients' immediate family members. The need for care is reassessed every six months;

the personal budget is calculated by multiplying the assessed intensity of care (in terms of numbers of hours) by the registered price per hour of the services judged to be required. The clients' contribution is assessed through income testing, in the same way as it is for care in kind. The aggregate total budget for care allowances is set at a national and regional level;

apart from an annual direct payment of Dfl 2,400 a year (about \$1,200), the client is not allowed to access the allocated care allowance directly. An association of 'personal budget holders' acts as an intermediary between the client and provider in arranging care, and the financial arrangements are handled by part of the Dutch Social Security Ministry.

The introduction of personal care allowances was, and still is, controversial. Interest groups representing the disabled keenly advocated the introduction of care allowances, believing that control over the care budget would give care recipients more freedom of choice in deciding on the nature and intensity of care provided. However, there was opposition from a variety of sources. Established providers were worried about their market share, unions were concerned that agreed pay rates/norms and conditions would be violated by individual clients, and Government agencies were worried about cost containment and the loss of tax revenues to a black market in care.

To get around these tax and pay rate concerns, the Ministry of Social Affairs and the Ministry of Finance agreed to cap the budget at no more than 5% of the budget for home care. They also agreed to set up an 'association' of budget holders who would pay providers and make relevant premium, social security and tax payments, while leaving the client in control of the selection of providers.

But this compromise has led to various drawbacks. First, since the budget is capped at a total and regional level, waiting lists are a common phenomenon since, if the annual budget has already been spent, clients are forced to wait. More importantly, the restricted overall/macro budget severely limits the possibility of transforming an oligopolistic (and sometimes monopolistic) care structure into a more diverse, competitive health care market. As a result - according to the Netherlands Institute of Care & Welfare - managed competition has not yet really materialised.

Nevertheless, personal budgets have had some positive results in the guise of a reduced client flow into institutional care, a more efficient use of resources and better integration of older people into the community. On the down side, evaluators believe that family members' decisions to help elderly people are only marginally influenced by the existence of a financial incentive.

### **1.6.3 Independent living: housing and care**

The history of Dutch housing is probably fairly typical of other northern European countries. After the Second World War, there was a considerable housing shortage which necessitated a substantial apartment building programme. Since the budget

was tight, the housing for non-handicapped/frail seniors was built with minimal space and quality requirements (only one bedroom, no lift, not wheelchair accessible and a maximum size of 30 sq metres). These homes, built by the Ministry of Housing, formed the first of three tiers of housing for the elderly.

The second tier consisted of the traditional 'old age home' or 'sunset' home. These were also built by the Housing Ministry but were financed (as they were in the UK under the old passporting of income support) by the Ministry of Welfare. There are 1,500 of these in the Netherlands, accommodating 130,000 elderly people (6.5% of over 65s), with an average age of 87 years. The large growth of this sector - making it proportionately the biggest in Europe - is attributed to the weak tradition of contacts between elderly people and their children. The third tier - increasingly hard to distinguish from the second tier - is the nursing home, which accommodates 60,000 people (3% of over 65s), including an increasing proportion of people with Alzheimer's disease. This accommodation has always been the province of the Ministry of Health. The typical arrangement is rooms with 4 to 6 people with the ability to move beds in/out of rooms.

None of this type of accommodation - except possibly nursing homes for the extremely frail (but even this is questionable) - is now deemed to adequately respond to the needs for privacy, dignity and adequate facilities for the aged. Dutch people are universally demanding a better standard of housing. But one of the important policy questions concerning care for the frail, elderly and chronically ill is whether better housing, if it were to be built, would enable people to maintain a more independent lifestyle. Policymakers typically assume that an extension of sheltered housing and improved neighbourhood facilities - shops, public transport, amenities, etc - will reduce the demand for institutional care. But research shows that so far, controlling for need variables, special housing schemes for the elderly have not reduced the demand for institutional care or yielded greater cost containment. Indeed, living in congregate housing has been associated with a relatively higher usage of professional home care.

Even more worrying for policymakers who believe that housing and general health should be correlated, deficiencies in the physical condition of the dwelling unit do not seem to affect the use of home care or the demand for institutional care. The SEV has not been able to prove any (negative) correlation between housing standards and care loads/volumes. The lack of neighbourhood public facilities, however, does seem to have a small effect on the demand for residential and nursing homes. Against this, in Sweden, an evaluation of new care settings versus 'normal' care settings has found that more homely settings reduce the need for care (see Swedish chapter for more details).

Several explanations have been offered for these findings, which may go some way to restoring a faith in the link between improved housing and greater independence. First, local governments and providers have had cautious admission policies for admission into sheltered housing schemes - in practice, these have been targeted at the less severely disabled elderly. Second, existing funding regimes do not allow flexible service packages - complementary to home care - to be put together for people living in their own homes with serious disabilities and weak informal support. Third, new care arrangements and better dwelling units are typically taken up by the

middle classes of society, who can afford the relatively higher costs leaving poorer and perhaps sicker clients unprovided for.

As a result of these problems, ie the need for more targeted home care support, the Dutch have developed programmes of 'very sheltered' housing, which offer additional services and support above regular community help. These projects are the product of the joint efforts of public housing corporations, home care agencies and homes for the elderly (see Humanitas and De Woonplaats examples below).

In most projects, a case manager is appointed who has to arrange for packages of care based on the individual's needs. If a client's health status worsens, the intensity and type of service can be adapted without having to be permanently admitted to an institution. Evaluation of these projects so far shows that they have improved effectiveness of care, thereby reducing admissions to institutional care, increased efficiency (same quality of care provided at lower total cost) particularly for residential care clients and slightly improved well-being but had little effect on the need for informal care.

#### **1.6.4 The future: a need for system redesign**

Integrated long-term care is seen as central to Dutch policy at national, regional and local levels. The objective is to set up in each region a 'network' organisation which brings together providers of home care, residential homes, nursing homes, sheltered housing and voluntary help operating as an authoritative local decision-making structure.

The goals are to enhance inter-professional co-operation, increase service flexibility, improve the quality of care and client satisfaction, enabling clients to maintain an 'independent' lifestyle and thereby reduce the numbers of people going into institutional facilities. The longer-term aim is to substitute home care for residential care through increased domiciliary care and sheltered housing/assisted living packages and provide 7 x 24 hours of care through nursing care at home packages.

The Dutch see three building blocks in this strategy:

- sheltered (and very sheltered) housing schemes;
- an expanded and well-regulated home care sector;
- allied welfare services (meals on wheels, etc).

Alliances between the first and third elements have already developed and it is anticipated that stronger links between care and housing organisations will take place, too. Housing associations are expanding housing for the elderly and disabled, but the twin pressures of market competition and political pressure from the elderly themselves will increase the need to build alliances with service providers.

Pilot projects encompassing the planning and funding of long-term care, needs assessment and service delivery have been set up in cities and rural areas to look at the consequences of building integrated service networks. 'Transmural' care is an interesting new development that involves working across the boundary between 'care' and 'cure'. Under these arrangements, qualified hospital nurses and personnel

in primary health care work together in providing care for the chronically ill and the very dependent elderly. In Rotterdam, there are experiments where care is provided to terminally ill patients in their own home. The care package involves:

- a home care team (GP, nurse, home care worker, etc);
- one person designated as the care manager;
- a nursing home place provided, and available, as a last resort.

The availability of a nursing home place, in particular, seems crucial in facilitating care at home. The point was made on our visit that, although often not used, access to respite care, a guaranteed nursing home place and alarm systems are crucial in allowing the vulnerable elderly to stay at home.

Academic research indicates that the efficiency of long-term care provision could be improved by a combination of providing better services and providing existing services better. Examples include the provision of more intermediary services, better collaboration between agencies and between sectors, and more innovative methods of delivering services. Some also believe that a personal budget or voucher regime could improve efficiency by even more than new structures or funding systems. That has yet to be properly tested (see US chapter for experiments with Cash & Care).

The overall conclusion from Dutch care experiments and innovation carried out to date is heartening. It seems it is feasible to set up a network organisation which is competent in providing flexible care arrangements within a given regional budget, where the organisation is made accountable for the efficient use of resources and is innovative in responding to the demands and preferences of clients.

## E1.7 Best Practice Examples

### Example 1: The Humanitas Foundation - 'Apartments for Life'

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The Humanitas Foundation was founded in 1959 in response to the poor and cramped condition of housing for the elderly after the Second World War, where people often shared rooms or had bedsitters, which in turn led to dependency and inactivity. The concept Humanitas has developed is a high-quality housing environment, which stresses independence and self-motivation in an environment that strives to be integrated with the community.

Humanitas is a non-profit provider of housing and home care, as well as nursing and treatment. It is currently based in Rotterdam and is one of the largest organisations of its type in the Netherlands. Humanitas raise funding from the capital market through the Trust Fund for Housing. They are currently investing 50-60 million guilders a year to create 300 to 500 homes a year.

They run 19 facilities, including 2 nursing homes, 5 residential care homes and 5 large apartment complexes. 1,500 people are employed and around 3,500 elderly live in their houses, residential and nursing homes, with a ratio of rental to owner occupation of nearly 6:1. Clients are referred from the Rotterdam Housing Authority and health boards following a multidisciplinary assessment. About one-third of the intake is healthy people over the age of 55; a third are registered as needing care and a third are assessed as needing nursing care. Average rents are about 800 guilders (£250) a month. Those on a low income (on a state pension) can receive a Government subsidy of around 350 guilders a month.

#### The Humanitas philosophy

The striking aspect of this organisation is not so much the type of housing they provide - which is as good if not better than other leading-edge providers - but their philosophy, which is based on a client-centred approach where the problems of managing integrated care are approached from the position of the client as care demander. Humanitas recognise that people do not enjoy coming into contact with health care institutions such as hospitals, nursing homes or old people's homes. People will not visit such institutions if they can avoid it - let alone live in such a place.

There are several facets to the Humanitas philosophy:

client responsibility and self-determination is key - people are encouraged to

do as much as possible in their daily lives themselves - they call this the "care with hands on our back" approach. In discussion, they freely admitted that some care staff found this 'non-interfering' (and non-patronising) approach hard to learn and implement at first;

the client, and chosen volunteers play a major role in their own care - care is given on a "use it or lose it" approach, which applies to muscles as well as brains, and "too much care is worse than too little care";

the client is 'master' of their own house. This necessitates a separation of housing and care - Humanitas dwellings are 'Apartments for Life', ie that care up to 100% nursing home care will be rendered in the client's own home with no need for separation from life partners. Even severely frail people will be accepted, eg a typical apartment block will have 20 people with Alzheimer's disease out of 250 residents. Residents pay their own rent and expenses for services such as the warden, window cleaner, etc;

Humanitas strives to stimulate direct communication with the neighbourhood where the housing is located so there is interaction with other population groups and social organisations - they see this as a move away from institutionalisation and towards reintegration.

The organisation bases its care concept on the desires put forward by individual elderly and pressure groups, namely: to function as independently as possible; to be able as partners (or parent/child) to stay together; more privacy; no need to move when more care is needed; separate bills for housing and care; to be able to live in one's own neighbourhood to maintain social contacts; control over who/what care is provided; care should be in a 'coherent' package.

#### Housing and care specifications

With respect to housing, Humanitas believe these desires translate into:

*adequate size* ie 3-room apartments - a minimum of 70 sq m (crucially, allowing a small second bedroom and a separate living room / bedroom);  
*safe and well designed* for older people, ie wheelchair and stretcher accessible and conforming to public housing and health & safety standards;  
*technically well equipped*, especially in the kitchen and bathroom;  
*adaptable*, so that future technological developments can be accommodated.

In the care field, this implies:

much *more co-operation* between the various organisations and professions;  
the care supplied and paid for must be *strictly necessary*,  
care should be *supplied anywhere* that the client wishes.

The idea is that the 'Apartment for Life' concept, together with the care principles, offers maximum opportunities for the elderly to look after themselves and be independent. Because the patient and client is no longer forced to move, remains in control of their own home, interacts with the outside community and has their own

interests and activities, social networks remain unimpaired. This, in turn, strengthens the desire of the elderly to take care of themselves as long as possible. Care is provided by several suppliers, with coordination of care being of central importance and enforced through a care contract. A permanent care manager records the client's care needs in one place and on one form and is responsible for fine-tuning care demands. Self-management by the client is the number one priority, and the client determines supply in terms of volume, nature and time.

We visited one of their residential housing projects - Humanitas Akropolis - in Rotterdam. Besides the comfortable apartments with balconies, which could be rented or owned, one of the striking aspects was the attention paid to the design and architecture of the buildings. The Akropolis project has a large glass atrium which houses the pleasant 'Grand Cafe' on the ground floor of the project with a first-class buffet restaurant. Other facilities in their housing projects include a sculpture park and a 50-metre long indoor pond with Japanese koi fish. The aim here was to emphasise everyday activities and recreation instead of the possible personal limitations of the inhabitants.

### Comment

The Humanitas concept is relatively unusual in separating out housing and care. But is it realistic to provide such high standards of housing and care with limited public and private budgets? Walking around the facilities, it was evident that the people housed in the building were ordinary citizens. One of the most encouraging features of the Humanitas concept is that this form of care does not come at a financial premium. Humanitas buildings cost 25% less than providing standard residential or nursing home care. There are a variety of reasons for this cost difference:

- 3-room apartments are 25% to 35% cheaper than a nursing home place; cost is kept down by maximum use of the assistance provided by partners, relatives and volunteers;
- the occupant's own housekeeping budget is invariably less than the cost of providing institutional meals/housekeeping with the inevitable overheads;
- finally, in a client-centred setting specialised psychosocial help is needed much less frequently, saving the high cost of care provided by psychologists, welfare workers, occupational and other therapists.

## **Example 2: De Woonplaats Woningcorporatie (Housing Trust)**

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De Woonplaats is a good example of a independent and self-financing housing organisation whose objective is to provide housing for rent for people on low incomes. They were formed in 1995 from 3 local housing associations based in Winterswijk, Groenlo and Outen with the aim of pooling their resources in order to grow and develop more effectively. De Woonplaats is another Dutch example of the separation of housing and care. It specialises in housing provision - building and maintaining their own properties, but they are also increasingly taking over the housing provision for care organisations and working directly with care providers, who provide everything from basic housework services to internal medical procedures in the home (intravenous injections, etc).

The organisation provides places for relatively low rents - around 750 guilders (£250) a month - by using profits from sale of houses to cross-subsidise its existing rental properties. As with Humanitas, their low income clients can receive a means-tested housing subsidy from the Government (maximum 250/300 guilders a month). The organisation insists that people are responsible for their own housing costs. This has the benefit of avoiding the problem in the UK where people build up rent arrears but still rely on local authorities to find them housing. De Woonplaats operates a systematic rent collection policy with warning letters followed by eviction.

### Comment

This organisation is another example of a body that questions the need for the elderly to live together in one institution. They, instead, believe that people will want more privacy and control over their housing environment and that the future lies in the elderly 'shopping around' for care packages. Since people do not like moving home once they are elderly (65+), homes need to be planned which take account of the likely greater incapacity of the residents. This links in with a UK initiative by the Joseph Rowntree Trust, who have produced a brief on 'lifetime homes', which has now been incorporated in UK building regulations.

If housing and care are to be separated, and increasingly dependent people provided with services in their own home, then clients need to be able to receive a very broad range of services from care providers. This is likely to be produced most effectively if there is a single budget for care.



### **Example 3: Stuurgroep Experimenten Volkshuisvesting (SEV)**

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The Netherlands is the only country in Europe which has an independent experimental organisation for the housing sector, financially backed by central Government. The Steering Committee for Experiments in Public Housing (SEV) was set up in 1982 to run experiments to demonstrate the practical value of innovations in public housing to improve housing quality, affordability and resident involvement.

The aim of the organisation is to support and stimulate local initiatives for innovative projects, which might be an example to others. Its main goal is that the results of experiments should be taken up by the mainstream of public housing. It is an independent body with an annual budget of about 7 million Dutch guilders (about £2.5 million). It is principally financially supported by the Ministry of Housing, Spatial Planning & Environment. Other ministries such as the Ministry of Health Welfare & Sports, the Ministry of Economic Affairs, the Ministry of the Interior and the Ministry of Justice all provide project related subsidies. The projects on aging and the handicapped are being sponsored by both the Ministries of Housing, and Health, Welfare & Sports.

Innovation is not a panacea for all public housing problems. But the SEV believe that experiments can offer a new solution to the challenges facing public housing officials and planners, including in the field of housing and care of the elderly and disabled. SEV therefore run a wide range of experiments, providing organisations with expertise, money, publicity and networking across a wide range of areas, including:

- policies of housing associations and municipalities;
- the construction industry;
- the building process;
- the organisation of maintenance;
- the ownership relationship between user and home.

Some large scale experiments have led to changes in policy, eg inclusion of the requirements of adaptable building in the Building Regulations or the Senior Citizen Consumer Label (see below), which attempts to get more consistency in housing standards.

The SEV has attempted to answer some interesting questions, including:

- how can homes be built or modified so that people can continue to live in

them throughout their lives?

how should housing associations define their role in relation to their social tasks (eg providing safe & accessible homes for elderly) and new relationships with tenants?

### Comment

The SEV has clearly been successful in initiating change and stimulating good practice. The introduction of the Senior Citizen Label is one example of a successful experiment. In conjunction with the Netherlands Association of Senior Citizens, the SEV has developed a consumer quality certificate for ordinary housing for the elderly, formulated specifically with reference to the budget constraints of the social housing sector.

Hundreds of housing associations and project developers have applied for the certificate for newly built housing projects. To get the label, the project must comply with over 50 sets of standards and guidelines (eg on lifts, safety measures, etc) for housing for older people, including the 'adaptable building' standard.

Around a third of the Dutch population over 55 have some kind of handicap, which has a consequence for housing. Given that, together with handicapped younger people, 4 million people or around a quarter of the entire Dutch population are affected by their housing, the Government has deemed it to be important to fix a set of housing standards. In practice, this means that around a third of all dwellings needs to be adapted to the needs of elderly and handicapped households. Since it is difficult and much more costly to adjust the existing stock to new standards, this suggests that all newly-built housing should accord with the Senior Citizen Label standard.

SEV has also played a useful role in reducing inter-departmental tension in the housing area. For example, they worked with an independent commission which was set up to reduce tensions between health and housing ministries when their interests diverged to produce an acceptable outcome. SEV also give advice to ministers, through biannual presentations about local developments, which helps to keep the ministries up to speed with local issues and practices.

# A STUDY OF THE BOUNDARIES BETWEEN HEALTH AND SOCIAL CARE FOR OLDER PEOPLE IN DEVELOPED COUNTRIES

## III. COUNTRY CHAPTERS

### F. GERMANY

#### F1.1 Summary and Overview

##### The Big Picture

The main features of the German long-term care (LTC) system are:

the introduction and bedding down of the **new long-term care insurance** arrangements, including interesting cash allowance options;

the **complex relationships between the various LTC players**: the state in its various guises, insurance companies and private agencies/welfare organisations who provide care;

the **implications of the new long-term care system for costs** and competition between providers.

Overall, the German LTC system works fairly well. The new long-term care insurance (LTCI) provisions - introduced in 1995 - builds on the existing system of social insurance and provides the fifth pillar in the German social security system. The new law is deemed to have been a success and has permitted the elderly to bequeath their assets to their children without imposing major costs on German society, thereby solving a major political issue.

Post-1989, there has been a tremendous improvement in the condition of homes for the elderly and a substantial refurbishment programme. We were told that the main beneficiaries of the unification of Germany have been the elderly - due both to higher pension levels, better care arrangements and improved housing.

However, there is a problem of bottom-up cost pressure on both the health and social care sides. Care providers - especially the social welfare agencies and health insurance funds - are under a fair amount of financial pressure, as premiums and care rates are very sticky due to political pressure from employers.

The system is heavily bureaucratic with detailed central legislation laying down assistance levels and remuneration rates. Services provided - and subsidy levels - are negotiated at state and local level between insurance companies, care organisations and state ministries. This results in a very complex system, which is arguably rather inflexible and one which consumers find difficult to penetrate.

### **The strengths of the German system**

The strengths of the German LTC system are:

there is **universal coverage**;

**consumers are broadly satisfied** with the care available. The choice between care-in-kind and the possibility of using cash allowances to 'tailor-make' their own care is particularly popular;

**the system is running a financial surplus**, partly through clever design;

**domiciliary care is mildly encouraged** through the law. However, the fact that people can claim DM 750 per month for day care and DM 2000 per month for institutional care is one example of a perverse incentive;

**inter-generational tensions are reduced**, since receipt of benefits is not age-related.

### **Weaknesses of the German model**

There are 3 main weaknesses of the long-term care insurance (LTCI) system:

in a complex system, **consumers find it very difficult to get information** about the range and types of care available;

it is **hard to get correct or satisfactory care packages arranged**, although a new network of independent advice centres will help remedy this problem;

**financially, the system may come under pressure in the medium-term.** Taxes might need to be raised - either the current federally set 1.7% contribution rate or local taxes to meet increasing welfare costs - if staff costs rise significantly or quality needs to be improved.

Other problems include the fact that providers find the environment challenging as they are under pressure to deliver high quality at low cost. Quality assurance can also be weak, and the initial care assessment is done very quickly. Cities and municipalities are also very hard-pressed to meet welfare payments through local revenues given the increasing numbers of unemployed and asylum seekers.

The 1994 Long Term Care Insurance (LTCI) legislation has created an open, but not complete, market. The key need is to create more flexibility in the provision and the level of care, eg through independent agencies putting together packages of care together.

## Lessons for other countries

Interesting lessons worth following include:

the **LTCl scheme allows recipients to get cash rather than care-in-kind**. The elderly and their carers can thereby exercise greater control over the care package, which results in better tailored and more flexible care;

legal **provisions recognise the costs incurred by informal carers**. Respite and holiday care is built into the system, and social insurance payments are credited during the time carers spend caring for relatives, neighbours, etc;

**built-in fiscal incentives** mildly encourage home-based care as well as prevention and rehabilitation. The fact that the cash allowance option costs the public purse about 40% of the care-in-kind option also means that the LTC funds are now operating in surplus.

## **F1.2 The Strategic Framework for Delivering Long-term Care**

### **F1.2.1 The philosophy and framework of care**

The conception of care provision in Germany is that the central or Federal State legislates and sets the overall framework on the basis of the common good. Local care partners then negotiate on the terms under which care is provided. It is a central feature of the German system that private or community care providers are 'free organisations' and can only be brought into the system voluntarily.

Family, social and fiscal policy all attempt to allow the elderly to remain at home. The Federal Ministry asserted that its philosophy was increasingly client-centred: a clients' individual needs had to be determined and then the care provided to meet those needs irrespective of the time taken. Nevertheless, they acknowledged that since funding was not unlimited, the system had to have a means of ensuring that financial constraints did not result in low quality provision.

Germany is a corporatist state. In Germany, as in other Federal systems, like Australia and the USA, there is a complex division of responsibilities between the Federal Government, states (the Lander) and the institutions (insurance companies) who fund much of the care. The Federal Parliament passes laws and enacts statutory instruments but these are carried out and financed by the Lander. The Federal Government heavily subsidises the welfare net (supplementary benefit, etc), but social assistance funds at local level in practice provide the care.

### **F1.2.2 The care model - an incremental insurance system**

The German health and social welfare system has developed incrementally, based on an insurance structure developed under Bismarck. There are three original pillars of this structure - covering health, pensions and industrial accidents - and unemployment insurance was added as a fourth pillar in 1927. Long Term Care insurance is the latest addition and came into effect on 1 January 1995. The aim of the system is that basic welfare for the needy should be met by local communities, while other eventualities, covered by insurance, are regulated by Federal Law.

It is compulsory for employees, blue-collar workers, training staff and other normally employed persons to belong to these insurance funds. Freelance workers and high income earners can join on a voluntary basis. 90% of the population are covered by this system. Individual insurance coverage is largely determined by the individuals' work place and type of industry. Pensions and long-term care premiums are determined by German law, while health and accident insurance premiums are set independently by insurance funds.

Retirement/pension insurance is arranged on a regional basis for blue collar workers, while for white collar employees insurance is organised nationally. This leads to an interesting tension between the Federal and state governments as the former are trying to centralise, while the states are trying to maintain a regional structure of provision.

Health insurance is provided by six different types of providers, with membership based on professional categories. There are, for example, many independent employers' organisations, an organisation for craftworkers, a state insurance provider, etc. In total, there are around 400 statutory health insurance funds. Since 1 January 1996, competition has been introduced and people have been allowed to choose from different funds. Despite some variance in contribution rates, fund switching is, however, still relatively uncommon as people hold allegiance to their local or employer fund.

## **The 1995 Long Term Care Insurance System**

Around 1.2 million Germans are living in institutional care, and there are around 15,000 places in day care centres. The number of domiciliary care service providers has risen from 28,000 in 1994 to more than three times that number today to around 300,000 people.

The **Long Term Care Insurance (LTCI)** system builds squarely on the existing health insurance arrangements. It is based on three clear principles - solidarity, plurality and self-administration. The *solidarity* elements are:

All people employed or resident in Germany are covered. As with current rules on health insurance, certain groups (eg high-income earners, freelance workers, etc) are free to opt out if they can prove adequate coverage through private care insurance. Insurance is non-contributory for the employee, and non-employed spouses and children are included free. Benefits relate to individual needs and are (importantly in the German system) based on a uniform list of benefits;

the scheme is financed on a Pay-As-You-Go principle by equal contributions from employers and employees, including present pensioners and those receiving care. This ensures that younger groups help to pay for the care of the elderly and the healthy contribute to the costs of looking after the sick;

contributions are related to income so that the rich subsidise the poor.

The *plurality* principle means that there are a wide variety of funds to choose from including 16 local or general public health funds, white collar health funds, Company and Guild insurance funds and specific funds for particular occupational groups, eg sailors, miners or farmers. *Self-administration* means that public bodies are under Government supervision; each fund has one administrative council which is responsible for setting contribution rates and a full-time executive board with employee and contributor representatives.

### General provisions

Under the LTCI provisions, it was a very important part of the 1994 agreement that the care insurance was integrated into the health insurance system. Hence Care Funds were set up as part of the statutory Health Insurance Funds: if someone changes their health insurer, they automatically change their LTC insurer. In law, the budgets and benefits of the different schemes are quite separate and defined. The

LTCI specifies which people are deemed to be the responsibility of the care funds - namely those who are in need of frequent or a great deal of help with normal day-to-day activities on a long-term basis (a minimum of six months).

The Medical Service (see below) is responsible for assessing potential clients into three care categories:

Care Level I: considerable need of care. Help is required at least once a day with personal hygiene, eating or with a minimum of two activities from one or more of the activities of daily living (eg housekeeping and mobility). Help is deemed necessary several times a week with household chores;

Care Level II: severe need of care. Help is needed at least three times a day with personal hygiene, eating and getting around. In addition, help is needed several times a week with household chores;

Care Level III: extreme need of care. Person needs round-the-clock help every day with personal hygiene, eating and getting around. In addition, help is needed several times a week with household chores.

The requirements state that if a person needs Level I care, they require an average of at least 90 minutes basic care every day of the week and help with household chores, with the care provider spending more than half this time providing basic care. If Level II care is required, at least 3 hours of help a day is needed with at least 2 hours being devoted to basic care; at Level III, the care required is at least 5 hours a day, with 4 of these hours spent on basic care.

#### Insurance payment rates

Home and institutional care is scaled according to the respective care level. The care recipient can choose between non-cash benefits, eg care provided by a social services agency and cash benefits, which the person can use to pay relatives, neighbours, etc. It is also possible to receive a combination of cash and non-cash benefits. For institutional care, the rates cover basic care, social services and treatment for the level of care you require. As with home nursing care, the care recipient is responsible for board and lodging costs. At least 25% of the nursing home charges must be borne by the individual and the amount of the care insurance is scaled accordingly up to a pre-set maximum.

The rate at which care benefits are paid is as follows:

<b>Home care benefits</b>	<b>Care Level 1</b>	<b>Care Level II</b>	<b>Care Level III</b>
Monthly LTC <b>cash</b> allowance	DM400	DM800	DM1,300
Maximum monthly total for <b>non-cash</b> LTC benefits	DM750	DM 1,800	DM 2,800 (DM 3,750)*
<b>Respite care</b> for up to 4 weeks a year by professional	DM 2,800	DM 2,800	DM 2,800



substitute or in a full-service care home (minimum. 12 months prior care required)			
<b>Respite care</b> for up to 4 weeks per annum by relative or other unpaid care provider (same conditions)	DM400	DM800	DM1,300
Maximum monthly benefits for <b>short-term day &amp; night institutional care</b>	DM750	DM 1,500	DM2,100
<b>Institutional care benefit</b>	<b>Care Level 1</b>	<b>Care Level II</b>	<b>Care Level III</b>
Basic care, social services and treatment in a home	DM 2,000	DM 2,500	DM 2,800 (DM 3,300)*

\* In cases of hardship

### Home-based care

Under the LTC insurance rules, the individual can determine their own care package. They can opt to receive care-in-kind at home or a significantly smaller cash payment to pay for non-professional care from relatives, friends, neighbours, etc, or a combination of care-in-kind and a cash payment, eg where a limited amount of professional help is required. In home-based care, 'soft' services are assumed to be provided by the family. Different professionals and agencies are involved in providing home-based care:

actual care on the body (nurses, care workers);  
 general care, supervision and guidance (welfare associations);  
 medical care (doctors, nurses).

The funding system for home care is (even) more complicated than for institutional care. Provider contracts determine the level of costs and if costs are greater than the amounts laid down by the LTCl, then the client is means-tested and social assistance is available. The benefits available for outpatient care are stipulated by law based on 4 criteria: personal care, mobility, nutrition and housekeeping. The payment system is based on 'benefit packages' (see Funding section below for more details), which are drawn up at a local (Lander) level by nursing staff attached to the Medical Assessment Service. Different care associations publish care packages and payment levels.

### Institutional care

It is a cardinal feature of the German system that anyone can set up and run a home or a hospital according to their own wishes. The home can consequently be built to any standard - the state only sets a limit on the price it is prepared to pay. Under the

social security system this price is negotiated. The rules state that:

nursing and residential care homes must have a contract with the LTC Insurance Fund and register with the state authority;

health and care insurance funds have to negotiate with the Lander;

homes are entitled to the price "they need to fulfill their job".

The LTCI provides care benefits, domiciliary and outpatient care as well as funding equipment costs (up to a limit). Remuneration rates in homes are negotiated on the basis of the condition of homes, running costs and levels of equipment provided. The Federal Government pays for the capital costs of new hospitals. The individual is responsible for their accommodation and housekeeping expenses.

There are several features of the German LTC scheme which are interesting, novel and/or worth imitating:

the scheme allows care recipients to get cash rather than care-in-kind. This (lower value) cash option proved even more popular than anticipated, with 80% of publicly-funded LTC recipients initially opting for this option. The main reason people gave for opting for it was the greater control it gave them over the care package, resulting in better tailored and more flexible care. The fact that the cash option cost the public purse much less has meant that the LTC funds are now operating in surplus;

there is a recognition of the costs incurred by informal carers. It builds in respite/holiday care as a standard option: funded respite care is available if the usual carer(s) is ill and relatives providing home care may take 4 weeks holiday a year during which time the LTC insurance fund will pay for professional home care services up to a set limit (originally set at DM2,800). Furthermore, social insurance payments are made for carers for the time spent caring for relatives, neighbours, etc;

the scheme has an in-built bias towards the provision of care in the home. Benefits for home care services were introduced before the benefits for nursing home services. The scheme also states that prevention and rehabilitation paid for by health insurance funds should be fully utilised before providing long-term institutional care. Equipment - and housing adaptations - are provided as a cash benefit (up to DM5000) with 10% of the cost paid for by the applicant.

Problems with the system (some of which are picked up later in the Issues section) include:

the LTC framework is one of the most detailed, prescriptive and regulated in the world. But unbiased information is hard to come by and, as a result, the system is a maze to consumers and even to workers within the industry;

the care classification is somewhat crude, and there is evidence that people

are not getting the care they need. Furthermore, as only defined 'packages' of care are available and only definite tasks are remunerated, softer and/or less easily pigeonholed tasks can be easily overlooked and left undone;

prices charged by care homes vary greatly (from DM 2,500 to DM10,000 per month) but it is not always clear what the individual is paying for. The Federal Ministry estimated that with greater transparency and proper management of staff (who account for 80% of care costs), care costs could be cut by one-fifth nationally, saving billions of DM;

Care of the elderly is rarely overseen by a specialist in care for the elderly - there are only 4 chairs in university medical schools which teach geriatric care. Hence there is a deficit in training and skills around care for the elderly.

### **F1.2.3 Long-term care funding**

All LTC prices are negotiated and all parties - the state, the insurance funds and the individual - are involved in funding the system. The way the funding works is as follows: care needs are paid for by the health and/or care insurance funds up to a given amount. If there is a shortfall in funding, eg because the institutional place costs more than the allowances, the individual has to find the difference.

The system specifies that board and lodging is paid for by individuals themselves. The Federal Ministry gave three reasons for this. First, there was a worry that all the costs of institutional provision would fall on the public purse, and families would keep the old age pension unless this was ruled out. Second, people would pay accommodation costs if they were living at home anyway. Third, a desire to promote home-based care and not pick up the costs of lodging was one way to do this.

While there is a single lead provider, several organisations will share the cost of providing services, eg the Health Insurance and LTC Funds plus the individual themselves. For example, typically a day rate will be negotiated with the care fund and if that proves insufficient then the patient contributes. If the individual's resources run out, then call can be made on the local Sozialhilfe or Welfare Funds. Private organisations and homes have never received any direct funding from the state. They have had to compete on price and convince people to use their facilities.

Long-term care insurance is financed through income-related contributions. The same contributions ceiling that applies to health insurance also applies to LTC ie a maximum income of DM6,375 per month (DM5,400 in the Eastern Lander). Benefits for home-based care were claimable from 1 April 1995 and institutional care from 1 July 1996.

The contribution rate was set at 1 % from 1 January 1995 and raised to 1.7% from 1 July 1995, when home nursing benefits were added six months later. The contribution costs are split equally between employee and employers. To compensate German employers for the 1% tax increase - arguably inadequately and inequitably - the Buss-und-Betttag public holiday (the Wednesday 11 days before Advent) was eliminated. Interestingly, when the rate was increased from 1% to 1.7%, no further concession was made to German employers.

## The 'Complex Fee' remuneration system

There is a 'complex fee system' for remunerating care provided in the home. Insurance companies can either pay providers for the time taken in providing a service or on the basis of the sort/type of service provided. In order to remunerate on the basis of services, a structure is required to set different services and packages in relation to each other to determine the amount of effort, time and cost involved in each service. Hence, services are broken into between 100 and 200 different items and around 20 typical 'packages' of care. Each service is allocated a given number of 'points' (eg small morning toilet is worth 100 'points', etc). The care insurance funds then negotiate a 'point value' with providers at a regional level (eg currently 1 point is worth around DM7).

The peak body for the care industry prefers the latter system as they believe that care needs are better conceptualised in terms of the care needed rather than time taken. Care needs to take account of fluctuations in individual circumstances.

Funding of institutional care or inpatient care works as follows:

the care funds contract with facilities so that the institution can be entitled to provide care and able to offer benefits under the LTCI provisions;

a second contract, which is usually annually negotiated, specifies the remuneration which will be provided. Payment is broken down into four components: care provision, accommodation, investment and additional specific or exceptional benefits. All payments except the additional benefits are agreed between the care funds and the facility. Exceptional benefits are agreed between the individual and the care funds.

If the individual cannot meet all the accommodation costs (average of DM35 to DM40 per day), for which there is no state payment, an income and asset means test is applied before access to social welfare (Sozialhilfe) is granted. Under this test, an individual's home is at risk if their income is insufficient. But few cases of this sort are likely as these costs are relatively low and, in some areas, applicants can apply to the Regional Welfare Fund for help both with 'hotel' and care costs.

## **F1.3 Roles and Responsibilities of Different Agencies**

### **F1.3.1 The Medical (Assessment) Service**

People applying for care are assessed on behalf of the health/sickness insurance funds by doctors from a separate Medical Service (MS). There are around 2,500 doctors, who are paid by a levy on all health insurance funds. The person's medical background is assessed along with their care needs. Four dimensions of care are assessed: personal care, nutrition/feeding, mobility and housekeeping, and potential clients are placed in one of three categories (One - lowest - to Three - highest) according to the amount of assistance they are deemed to need. The doctor will usually ascertain the client's hospital record and will talk with their GP and consult

relatives and carers. The assessor not only makes a recommendation concerning the care level, but also looks at the need for rehabilitation and makes a recommendation for the use of health/care insurance.

There are several weaknesses in this system. The process came in for a fair amount of criticism during our visit and there seems to be a case for change. First, the MS assessment has a risk of being subjective and based on a 'snapshot' visit to the patient. The insurance funds confirmed that the image of the MS was not very good. Although doctors were heavily constrained by rules in the assessment process, doctors in the service have very different skills and aptitudes, which meant that different decisions were taken in similar cases in different parts of the country.

Second, the process of a fixed 'visit' and the strict categorisation left the process open to being 'gamed'. Indeed, some of the people we met said that there were cases where an individual old person either made a superhuman effort to appear as well as possible and thus failed to be given the correct assessment. Or, they were 'prepared' for the visit by social workers and carers with the objective of appearing as sick as possible in order to qualify for a higher care category.

Third, the assessment process appeared unduly strict, although it must be noted that this was a provider view and they clearly have a vested interest in securing higher care assessments. For example, it appears that elderly people with dementia are routinely classified in the lowest care category (I), whereas they actually have quite extensive - even 24-hour - care needs. The care level is assessed only on the basis of somatic not psychiatric disease. Anecdotally, we were told that if someone could even get to the door, they were automatically ruled out of the Level III care category.

Finally, it appeared that there is evidence of systematic over-prescription of tranquillisers. We were told by one leading Fund that 15-20% of people diagnosed with Alzheimer's disease are prescribed tranquillisers. These drugs reduced cognitive ability still further and worsened the prognosis for these patients. Patients were also more likely to have hip fractures and resulting expensive care as a result of being drowsy.

### **F1.3.2 Health insurance ('sickness') funds**

There are a large variety of different funds catering to different professional and trade groups as well as occupational classes. The basic (blue-collar) funds cover 40% of the total insured population on an individual state basis (eg A.u.K in Nordrhein-Westfalia covers 3 to 4 million people) - around 40 million people. There are around 400 to 600 funds, which vary in size from 20,000 to 30,000 with a single large employer, to Barmer Ersatzkasse, who we visited, with 9.2 million members (see below for Barmer's work on hospital discharge management).

95% of treatment is covered by the benefit-in-kind system offered by sickness funds. The funds all offer the same kind of medical care and, by law, the funds have to contract with any services (eg hospitals) or doctors that wish to treat their clients. Despite offering the same services, the funds charge different premiums (eg Barmer Ersatzkasse charges 13.9%, slightly above the average amount) because premiums

charged are a function of the total fund income. As the required coverage of benefits is set by law, and the actuarial likelihood of morbidity is not likely to vary greatly by area or type of member given the numbers of people involved, total fund income is what in practice determines the premium rate.

A reform in the legal structure of the funds in 1993, around the time of the introduction of the new LTC insurance, had two main features. First, it introduced the concept of 'risk structure balance', where funds with higher income would support lower income funds. Second, for the first time it allowed people to have a free choice of sickness fund with the aim of engendering competition between funds and lowering premiums (since benefits were predetermined). In practice, some younger, healthier people have migrated to lower premium schemes but most have stayed with their original scheme.

### **F1.3.3 State and local government roles**

Under Germany's federal system, many responsibilities of basic legislation are passed down to states and city-states, eg the operation of police forces. Regions have their own government and some, like Bavaria or Nordrhein-Westfalia (which we visited) with a population of 12 million, are significant economic entities in their own right.

With respect to long-term care, local government essentially carries out Federal law. The law determines care entitlement and contributions and finance is arranged at a Federal level. The state has a responsibility to provide a service if a need is proven, eg to ensure there are sufficient residential care places as well as ambulatory and domiciliary services. We were told that the rubric was that "care should be sufficient but not uneconomic." States do, however, have some discretion to provide additional services, eg Nordrhein-Westfalia provides services and information for psychiatric services, home adaptations, family care and counselling, which are not formerly part of the LTC law.

Both local authorities that provided communal services and cities, who fund social assistance costs, saved large sums of money as a result of the introduction of the care insurance law. Nationally, the former saved DM 3 billion as a result of the new LTC law, and cities in Nordrhein-Westfalia alone saved DM 220 million through lower social assistance costs. Partly as a result of this unexpected transfer of funds, states are broadly happy with the LTC insurance system.

### **F1.3.4 The private and voluntary sector**

Once the state has established that there is a need for services, welfare agencies, etc, are consulted, and one organisation or provider will be chosen as the lead agency for a given person's care. Private sector care provision has grown to fill gaps in public services as people working in the formal care and medical sectors have been motivated to leave and establish an independent service. Local Sozialhilfe (Social Welfare) organisations fund and operate advisory centres and meeting places in local cities and rural areas.

## **F1.4 Delivery of Services and Accountability Mechanisms**

Services provided to individuals have to be negotiated with the health insurance companies ('Krankenkassen') or the state (Länder) if subsidies are involved. Usually the insurance companies are obligated to pay for certain elements of treatment and the state picks up the cost of the rest. For example, the insurance companies would pay for housekeeping and care services required because of incapacity, such as help with activities of daily living. The state will pay for social and psychological help; information on accessing care; advice on home adaptations; training for family members regarding caring; bereavement and death services.

The new Long Term Care Insurance provisions have affected how services are delivered in three main ways:

individuals are now allowed to charge many more services to care insurance funds;

the new LTC law allowed people or agencies to set up and charge the LTC Insurance Funds for services rendered which led to the number of care agencies rising dramatically (eg from 180 to 900 in the four years after the reform in the State of Saxony alone);

the law made a division between investment or capital costs and labour or running costs in delivering home care. Paragraph 82 of the LTC law defined investment costs (the cost of office space, all costs infrastructure connected with running an organisation and the purchase of cars, etc) and stated that LTC Funds were not liable for these costs. The Länder therefore pay these costs, eg subsidies, for nursing homes to be built or refurbished with 80% of the cost in turn coming from Federal Government.

## F1.5 Issues and Policy Debates

### F1.5.1 Is the new long-term care insurance system working?

The broad political and professional consensus is that the new LTC insurance is a marked improvement over the previous system. Its advantages are:

**people with genuine care needs now receive publicly funded care** and are not forced to spend their own assets and claim social security;

somewhat surprisingly, **it has brought costs back under control**. The long-term care fund is running a surplus (due to clever design - high take up of the lower cash option) of around DM12 billion. In addition, the reform has reduced social security costs by about the same amount since people no longer need apply for social security payments to cover care costs under the new system. The dependence of care recipients on supplementary benefit has decreased from 80% and 100% in the Western & Eastern Lander respectively prior to the introduction of statutory LTC insurance of 30% to 50% today.

Its disadvantages are:

the **system is highly complex**. It is hard for people to understand what options are available and then obtain the help they need. As a result of this 'information failure', the municipalities and voluntary organisations have set up advice centres where people can go and get unbiased advice;

many people complain that **help is not comprehensive enough**, eg for people with low level needs or, conversely, for dementia care. The Medical Assessment Service appears to place people in too low categories of care. Around a third of all persons assessed are denied care, and people still fall through cracks in the system - these people inevitably fall back into the social welfare net;

there is some **evidence that people are 'gaming' the system**;

**provision is too inflexible** and, for example, more flexibility is necessary in how respite care is provided;

there is **still a boundary between the LTC funds and the health funds**. There is growing evidence that the health funds are trying to shift costs onto the LTC fund. Consequently, the LTC system is trying to build up barriers towards people referred by sickness funds. Conversely, the health insurance system is bearing the costs of drugs (eg Esterhaze Inhibitors for Alzheimer patients) which delay the onset of disease and need for LTC. Sickness funds are also reluctant to pay for equipment needed in nursing homes.

Although the system has brought aggregate costs under control, the current system is still vulnerable to bottom-up cost pressures (from home owners, staff costs, etc) and, as a result, compromises in quality. The Federal Ministry asserts that, despite the system of negotiation over prices, there are inadequate incentives to keep the



price of institutional and ambulatory care down. The separation between the Federal Government and the Lander, as in Australia, and between health insurance funds and care funds means that parties are trying to cost shift onto each other and gain control of the system. The state has little interest in saving money in building hospitals as the bulk of the costs - the running costs - are paid by someone else, namely the health insurance companies.

Health care costs are determined 'bottom-up', eg through the basic salary costs of doctors, drugs, capital and equipment costs, etc. Hospitals, who are the largest single cost element in the system (costing DM 85 billion out of a total health care budget of DM 240 billion) are regionally funded and are demanding annual budget increases of 5% to 6%. The story with drug costs is even more alarming for the sickness funds with costs rising by between 13.5% and 22% from 1998Q1 to 1999Q1. As a result, the sickness funds are very worried about the spectre of rationing since they are squeezed between rising health care costs and strong pressure from politicians not to raise premiums. Higher premiums would knock onto wages and raise already high labour and associated welfare costs facing German employers, thereby potentially aggravating a deteriorating unemployment situation.

In a system that is publicly funded, there will always be financial constraints, and the easiest way to reduce costs is to economise on the quality of care. There are around 8,000 homes in Germany, but only a few people at state level to monitor prices and standards, etc. Long-term care providers saw the introduction of LTC insurance as an opportunity to set up business, but quality was variable.

#### Moving slowly towards better patient management

At the moment Germany has one of the highest average lengths of hospital stay in Europe at around 11 days. Some health insurance funds, such as Barmer Ersatzkasse, are beginning to act like US-style managed care organisations and - as purchasers - trying to improve the efficiency and effectiveness of the care system. The German system could evolve towards a managed care-type system if the funds employed doctors to argue for better/shorter duration treatments and they used the data on their clients which hospitals are required to give them as part of the contract.

This data allows the funds to look at comparative lengths of stay for patients of a given age group and the same diagnoses in different hospitals. The funds currently see a lot of wastage (eg poor outpatient treatment which necessitates much more expensive in-patient treatment later on) in the system - addressing this could save up to 10% of current hospital costs or DM 25 billion.

Barmer, for example, are looking at new ways of providing long-term care in order to get round the problem that the existing vertical medical and social care institutions do not cooperate efficiently. They are therefore looking at better discharge management. For example, typically a GP would send a patient to hospital, but not an outpatient specialist as he would be wary that the specialist would 'poach' the patient and the GP wants to make sure that the patient returns. The cost implications of this decision are enormous - for a patient with diabetes, hospital care is likely to cost DM 4800 (12 days x DM 400 per day), compared to around DM 600 for specialist outpatient care.

But persuading GPs to change behaviour is not easy and, as a more outpatient (O/P) focused service would imply higher costs in O/P care, even O/P providers do not want this as they feel this would discourage less progressive sickness funds from using their services. The question is how do you give doctors an incentive to use specialists where this is merited? Funds are experimenting with therapy guidelines which use test data, eg urine/blood sample test for diabetes, to determine which type of practitioner is seen and putting barriers in the way of hospital admission (eg more than one person's approval is required).

Sickness funds are also addressing the question of how you could move money from the LTC system, which is in surplus, to the financially constrained health system with a view to improving people's health. They are addressing such issues as disease management (using drug therapies and rehabilitation), better treatment methods and how the different parts of the care system can work better together. The funds are therefore interested in quality assurance and are increasingly sending questionnaires to clients to ask about service levels (eg occurrence of bed sores).

#### **F.1.5.2 Quality issues**

In order to deal with problems of low quality in care homes, the Federal Ministry are seeking to roll out a service and quality contract. They believe a contractual approach is warranted as the institutional and other care providers are not seen as subordinate units of the state but essentially 'free' organisations. They envisage that partners to this contract (homes, social/voluntary organisations, Lander, etc) will work out an arrangement laying down precisely what homes will provide in terms of care for individuals, eg the service level, quality standards, staffing ratios, etc.

The idea is that the contracts would specify that care providers (eg nursing homes) must be efficient, economic and adhere to a written commitment to total quality management. To enforce the contract, the state would take powers in this contractual framework to close down a home if it breached the terms of the contract, eg was deemed to be 'uneconomic'.

Another solution is through the improvement and development of Quality Assurance (QA) mechanisms, with a distinction drawn between internal and external QA. Some cities are establishing boards to check out quality standards. The Government has also sought to strengthen the accreditation approach - in line with other European countries, eg the Netherlands. Paragraph 80 of the LTC insurance legislation makes provision for agreements between health insurance funds and providers associations to implement QA. However, this agreement has now been terminated as providers felt there had been insufficient funds from the funds to improve quality.

Other possibilities include:

the TOV - the German Association of Care Providers - could monitor institutional care quality (internal QA). This solution has both the advantages and pitfalls associated with 'in-house' regulation;

Medical assessment teams could monitor institutional or domiciliary care

quality (external QA). This is rather a bureaucratic solution, in an already tightly prescribed system, and checks might be easy to evade;

quality could be predetermined by passing regulations about size, specifications and standards in flats and homes. This solution imposes the up-front costs of regulation indistinguishably on all providers and therefore could be less efficient in economic terms than building quality mechanisms into market provision;

the 'Advice Handbook' (see KDA example in Best Practice section) could be used in 'Quality Circles' to promote best practice. This has proved a useful way to change mindsets. The problem with this is that change is voluntary and depends on individual motivation and willingness.

From a consumer viewpoint, quality problems manifest themselves in other ways. People often want more 'care' than their condition warrants, and there is sometimes conflict between what it is deemed that the family should provide and what nurses should do. As a result, care workers and administrators believe that it is important that organisations have a clear 'contract' with the patients so that everyone is clear what services are being provided.

### **F1.5.3 Housing issues**

Federal and state government housing policy has several strands:

it is important to build living apartments that take the whole family's needs into account;

a recognition that many older people are poor - and in the Eastern Lander people are often moving into retirement from unemployment;

a range of living arrangements needs to be provided including group homes where the elderly can live together, mixed developments where the young and old can live side by side as well as residential and nursing homes.

Federal level housing projects (see section on the Kuratorium Deutsche Altershilfe [KDA] in Best Practice Examples below) have thrown up several problem areas:

no nursing care is often provided for people living in independent flats;

there are many different forms of assisted living, and people have difficulties finding the right level of assistance;

accommodation is available for people with high and very low incomes, but there are few suitably adapted flats for people with middle incomes, ie the ones that are available are either luxurious and expensive or only available to those applying through social welfare.

The Germans believe that mixed living arrangements - with older, younger people and families - can work well, but such projects need some help addressing the

problems which can arise in this kind of setting. Only a small percentage of housing projects are integrated, and the KDA believed that such living arrangements tend to suit more active or younger elderly. A larger proportion of projects - 3,000 complexes in Germany - are in the form of 'assisted living' homes.

A German 'norm' for an elderly-adapted apartment has been devised, and the KDA provides the secretariat for an umbrella association encompassing projects with 'adapted' flats. More adapted buildings, eg for the handicapped, are being built. Advice centres in cities and localities (Sozialstation) provide information about, and assistance with, procuring aids and equipment. These centres have departments for housing placement and advice on and for carers. About 95% of the elderly live in their apartments and are taken care of in that setting. Most older people live alone - mainly women who are widowed, divorced, etc. German municipalities are building specially adapted flats for the elderly in recognition of the fact that most elderly people want to stay where they are. There are a growing number of assisted living places, run by private or charitable organisations ('Volfahrtsverbender').

Housing adaptations are supervised by the Interior Ministry and, particularly in the former GDR, there is a generous new building programme. But this programme, which benefited from a very generous tax break, led to developers building homes that the elderly could not afford. As a result, the Federal and State Governments are subsidising a new programme of affordable, adapted homes. These are mainly flats with kitchens and adapted bathrooms so that the elderly can do everything themselves and get help with caring from a 'Sozialstation' if required. Rental costs are fixed (DM8,50 per sq metre) and there is a fixed care subsidy (up to DM100 per month).

We spoke in detail to the Dresden City Authorities. They had made major efforts in the area of elderly housing since in 1989 apartments were so poor that home-based care was often simply not feasible. However, although many people are moving into better accommodation, a lot of people still live in substandard homes. Assisted living or sheltered homes have proved a way of encouraging people to move as they have the incentive of benefiting from additional services.

In Dresden, the City Authorities had modernised nursing homes reducing the number of beds in a room from 6 to 2 to 3 and ultimately to single rooms and providing most rooms with ensuite toilets (previously 1 per floor). This had tremendously improved quality. Dresden has also undertaken a lot of refurbishment but is being very careful about how the flats were being modernised - key features are:

- a tight contract with the builder which specifies low rents in return for Satet investment and maintenance/upgrading of the surrounding residential area;

- a 'social plan' has to be in place;

- provision for temporary accommodation has to be made while someone's flat is being renovated.

#### **F1.5.4 Treatment of people with dementia**

There is insufficient provision for people with psychological problems, including dementia. This is largely the result of a care assessment system and insurance system which focuses almost exclusively on bodily, rather than mental or emotional problems. Other problems include the fact that the placing of people with dementia into a care category is variable; there is little additional incentive for organisations to look after people with these (heavy) needs; few dedicated facilities and places are available, and help for people in rural areas is particularly difficult.

People with dementia can require two or more people to look after them, but the current system does not recognise this extra level of needs. There is general consensus that there needs to be a change or amendment to the LTCI law to enable people with dementia to be cared for properly.

Nevertheless, some innovative arrangements for dementia clients have been devised, providing a very positive alternative to living in nursing homes. Typically, such a project would have 5 people living together in a big flat. The people in the 'home' would do the housework themselves (the more able helping the less able) and carers would come in to bring meals and helping with personal care tasks (hygiene, etc). Unfortunately, there are very few of these projects for people with dementia.

#### **F1.5.5 Issues facing care providers**

In Germany, nursing and residential homes are on the defensive because low care standards have been exposed in some homes resulting in 'scandals' and adverse nationwide publicity for the home care industry. People are beginning to ask why they should pay DM 6-7,000 a month for inadequate services.

Another problem is that time spent simply being or talking with clients is important to the care and recovery process, but no-one at the moment is willing to pay for this time, and insurance companies seek to pay for the absolute minimum of care. To remedy quality failings in this regime, the state and sickness/LTC funds inspect providers to ensure that standards are being maintained, which generates obvious tension.



## F1.6 Best Practice Examples

### Example 1: Kuratorium Deutsche Altershilfe (KDA)

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Founded in 1962, the Kuratorium Deutsche Altershilfe (KDA) is a non-profit research, information and publishing organisation dedicated to developing and promoting the latest models for providing services to the elderly. Its headquarters are in Cologne and it has an office in Berlin (since 1994) to provide advice and information to the new German Lander.

The fundamental objective of the KDA is to 'empower' the elderly. They work, whether on changing the care structure, promoting prevention or providing hands-on help on a number of levels: academic, ie theoretical/sociological; Federal politics; state/local government; institutional; infrastructure (eg housing) and through providing information and advice. Their overall aim is to improve the situation of older people who are limited in life activities as a result of illness, disability or other handicaps.

Over a number of years, the organisation has been in the forefront in Germany in initiating, financially supporting and developing a number of initiatives and services, including:

new and improved elder care services such as 'meals on wheels', day centres, respite and short-term care provision;

new models of housing, eg 'assisted living' arrangements;

consumer advice centres where people can get legal and contractual advice relating to their needs (55 of these centres now exist in Nordrhein-Westfalia);

a consumer advice handbook, based on the *Self-care Handbook* produced by Dorothea Orem.

The KDA brings together experts from Federal and Lander ministries, local government, health and care insurance schemes, welfare associations and academic organisations to look at the practical implementation of new and better ways of providing aid and services to senior citizens. Projects which the KDA are currently looking at include how to provide quality assurance in outpatient care, housing issues (eg appropriate forms of sheltered housing and mixed housing

arrangements) and devising new forms of help for those with dementia and other psychological conditions.

KDA are currently acting as the information hub - collecting information from twelve national coordination centres and running a database on behalf of the Ministry for Family Affairs for an initiative on housing. Under this initiative, several housing projects have been set up at the Federal level to pilot various models for living arrangements. In the projects, the views of residents are sought regarding their living preferences, along with the advice of builders and architects.

As early as 1973, the KDA was calling for improved care and security for those requiring nursing care for much the same reasons as now prevail in the UK - namely that health care was free, but nursing home care was means-tested and expensive. Aided by pressure from social welfare organisations in the cities, the KDA's calls were eventually heeded in the form of the introduction of a new long-term care insurance scheme in 1995. KDA's publicity material states that:

"...In the practical implementation of the nursing care insurance scheme, the KDA is making every effort to ensure that a quality of nursing based on modern standards is made possible and that this system helps maintain and promote the greatest degree of independence possible while providing support for senior citizens and handicapped persons in their daily activities."

Examples of the work the KDA is involved in are:

*helping to improve the domestic living arrangements of the elderly.* The KDA has stressed the importance of adapting dwellings to conform to the needs and living conditions of their elderly inhabitants through studies and sponsoring an exhibition;

*promoting a better quality of life at home.* The KDA has been working for improvements in dwellings and living conditions at home for over 20 years. Architects, economists, social scientists, gerontologists and psychologists have been brought together to study the location, interior design, organisation and financing of new buildings or the modernisation of existing homes. The KDA has compiled planning norms for nursing homes which serve as the basis for model institutions throughout Germany;

*calling for better qualifications and training for care workers.* The KDA is promoting continuing education and further education of people providing care to the elderly by organising workshops, devising educational tools and providing financial grants with funds from the Deutsches Hilfswerk (DHW).



## **Example 2: Caritas Verband**

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Caritas is one of the key voluntary welfare associations ('Volkshilfsverbände') in Germany. The others include the German Red Cross, the Jewish Welfare Association and the Diagonie (Lutheran) welfare organisations. Originally, there were 15 social services offices in Dresden - now there are 800 care agencies and around one hundred recognised ambulatory care agencies.

The history of the particular branch we visited in Dresden is unique: it was formed in November 1990 and based at a former multidisciplinary polyclinic. In 1991, they were the first welfare organisation in Eastern Germany to hire a social worker to help clients with paperwork. In Western Germany, home helps and social workers were in different organisations.

After the merger between the former GDR and West Germany, the doctors in the polyclinic dispersed to become GPs in private practice or specialists. Caritas and two other welfare associations received funds from local communities and the State of Saxony to set up an ambulatory care office on condition that the office was up and running quickly. It started in 1990 with a manager (Frau Jensch), 4 nurses, 2 people on community service and 2 home helps. Today, the Caritas Verband employs 34 employees, including 2 managers, 15 nurses, 6 home helps, 4 people on community service, 1 long-term care worker and a geriatric care worker.

When the new Sozialstation was set up in Dresden, managers from different disciplines and a representative from the Family/Elderly care Ministry was invited. But the new organisation had a lot of difficulties with the Health Insurance Funds who were trying to recruit new members and were unwilling to pay for equipment. Another problem that Caritas perceives is that the Health Insurance Funds are unwilling to pay for any care that is not directly related to medical care, and mental, emotional or spiritual problems get overlooked.

Caritas has a hospice for care of the terminally ill, carries out home hospice care and are building a palliative care institution. They are currently working on a plan with the hospital for provision of long-term care by nurses from different locations. The future does not look easy, as Health Insurance Funds are reluctant to pay for the full costs of care. While Caritas is bound to treat conditions according to given pay scales, other care agencies are not bound by these pay rates.

### **Example 3: Martin Luther Stiftung**

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The Martin Luther Stiftung was set up in the 1870s and is currently based in the town of Hanau, near Frankfurt. As its name suggests, it is a Protestant-based care organisation and was started by Protestant nurses who wanted to help the elderly in the area. It now has a turnover of around DM12 million (£4.5 million) and employs 500 people. It has around 400 people living in flats and apartments in the Stiftung and a sizeable welfare (ambulatory care) office, the Hilfezentrale - with its own Director - which employs around 1 in 5 of the organisation's staff.

The main work of the organisation is to provide domiciliary care and run and service 100 flats housing 250 people - a mixed population of some 'fit' elderly and some requiring 24-hour care. All flats are built in a way that can be adapted to the needs of the elderly person living there, have alarms and 24-hour care coverage, based in a central office. The typical occupant is a woman living on her own aged around 82 years old. In addition to the mixed flats, there is a specialist dementia home (the Gustav Adolf Heim) housing 50 people; 18 respite and short-term care places; 25 day care places and a rehabilitation service for post-acute patients with hip or stroke conditions.

The welfare arm of the organisation - the Hilfezentrale - serves 90,000 people in Hanau itself and a further 15,000 in the neighbouring rural area. The help centres serve 2,000 clients with frequency of visits ranging from once a week to eight times a day. The Hilfezentrale receives sponsorship from the Church communities and the City of Hanau Welfare Department. The Hilfezentrale is subject to the direction of an umbrella Old Person's Care (Altenhilfe) Group, who set overall policy direction and priorities.

The Stiftung employs 50 employees to provide home care, a meals-on-wheels service, home helps and housekeeping, an outreach and mobile social worker, therapists, 2 counsellors and a mobile library. All sections of the Hilfezentrale work together so that unusual absences, hospital visits or after care can be notified and arranged.

We noticed three innovative aspects of this organisation:

although the Stiftung is mainly a residential care provider, it has an on-site rehabilitation facility set up in the manner of a hospital out-patient department in co-operation with the City Hospital. Very unusually, the centre has a full-sized rehabilitation pool to encourage mobility. The consultant at the hospital supervises the doctors and other medical staff in the Stiftung. There are two

other sites - in Frankfurt and Wiesbaden - and a trial site in Hersen which offer this type of service;

the Stiftung runs a small educational facility/college for apprentice training for care assistants. Since there is no public training in the State of Hessen, the state funds the Stiftung to provide the 3-year apprenticeship course, and the Stiftung provides enrollees with wages equal to that of a care assistant;

the Stiftung has an innovative arrangement for night cover with the local hospital. A hospital sister always has a mobile phone on which emergency calls can be received from the flats. If the sister needs to make a visit, the costs are met by the insuree's health insurance or by the individual themselves if the care is not covered by insurance. This arrangement was brokered by the state and health insurance funds who wanted both lower lengths of stay and better after care. It benefits both the hospital - who get paid for delivering the care - and the Stiftung who saves expensive night-watch costs.

## **ANNEX 1: DEMOGRAPHIC TRENDS**

The population of Germany is around 82 million people, including 7.2 million people born outside Germany. Historically (between 1960 and 1996), the number of live births per thousand inhabitants has fallen dramatically - by 40% in the old Lander and 68% in the new Lander. Forecasts, in 1994, by the Federal Statistical Office were that the population will drop to just over 72 million inhabitants by the year 2040.

At the same time, as in other countries, Germany faces an aging population. Currently 22% of the population are over 65 years of age. This is anticipated to rise to around a third of the population in 2030. Of the 20 odd million who are over 65, around 1.6 million people in Germany today require long-term care. A quarter of these people live in nursing homes, while the remaining 1.2 million are cared for at home by relatives, neighbours, volunteers or professional care givers.

The new long-term care insurance and the stress on home-based care has meant that the entrance age to residential facilities has been rising steadily and is now over 82 years. Although the elderly are more independent as a group, when they become dependent and need institutional or home care, they tend to be sicker.

### III. COUNTRY CHAPTERS

#### G. SWEDEN

##### G1.1 Summary and Overview

###### The Big Picture

The main features of Sweden's long-term care (LTC) system are:

**universal provision** based on the philosophy of serving all older persons who need care equally, regardless of age, sex, ethnicity, place of residence or purchasing power. Swedish policy aims to guarantee older people a secure income, housing, social services and health care according to their needs, while maintaining freedom of choice and high standards;

a **decentralised** LTC system (significantly more so than the UK) with more than 80% of services financed and provided by local authorities. The latest round of reform in 1992 (Adel reform) devolved county responsibilities for care of the elderly (equivalent to UK NHS duties) onto the municipalities;

as a result, the **289 municipalities are dominant**, with wide responsibilities, control over service levels as well as care priorities, and receive most of their revenues from local taxes and fees;

but the **economic crisis of the late 1980s/early 1990s**, which led to a steep increase in unemployment, lower tax revenues and higher spending on social allowances, has enforced a change in social policy;

there have been **cutbacks in generous social services provision**, which existed up to the mid/late-1980s - mainly through tightening eligibility criteria;

**community care policy is strongly oriented towards home-based care**, although some elderly still tend to prefer residential care;

as elsewhere, there has been a large (40%) **reduction in hospital beds**, a de-skilling of medical personnel dealing with the elderly as a result of fewer geriatricians and a fall in average hospital length of stay from 7¼ to 5½ days.

The Swedish long-term care (LTC) system works well. It is, certainly by UK and US standards, extensive, comprehensive and, even despite recent cuts, well resourced. Services and care are largely financed and operated by the public sector, although there are a growing number of contracted out services. Health and medical services are highly subsidised (but not free), with recipients paying on average under 10% of the cost.

Sweden's 21 county councils are responsible for providing health care, while the 289 municipalities provide housing and social services. Swedes have a statutory right to claim service and care if they need it. The municipalities decide the structure, organisation and resourcing of elderly care according to their own priorities.

But during the 1990s, the LTC system has moved from a very generous general welfare model to a more mixed - through contracting out and higher fees - and selective - due to restrictions in eligibility and programmes cutbacks - system. Private for-profit care is playing a small but growing role. Overall service levels, in terms of the coverage ratio, have now dropped back to the level of the 1960s before elderly services saw two decades of strong expansion. The family, as in other countries, remains the backbone of care for the elderly.

The pressure of demography, due to a large baby-boom cohort in the 1940s, means that the population over 65 is due to rise from 18% to 25% of the population, and a growing number - around 1 in 20 - will be over 80. Together with the financial burdens on local authorities as a result of the economic recession in the early 1990s and the policy of caring for people in their own home, the Government decided that it was time to focus on laying the longer-term foundations for a secure LTC system.

After lengthy deliberations, the Swedish Government enacted the Adel reform in 1992, which transferred the responsibility for elderly (social) care to municipalities, introduced some new policy goals and aimed to increase the effectiveness and quality of elderly care by service integration and coordination as well as by commissioning new research. A National Action Plan on Elderly Care was passed by Parliament in June 1998 to address the Government's desire to devote more resources to elderly care. A new Parliamentary Commission, set up in May 1999 and due to report in 2003, is looking at the implementation of the new Elderly Action Plan and has a brief to look at longer-term problems.

## **Strengths and weaknesses**

The positive aspects of the Swedish long-term care system are:

the **scope, density and extent of care provision**. In return for high personal and corporate tax rates, there are generous welfare benefits, which guarantee a minimum income, and high levels of service and care. A relatively high retirement income, equivalent to two-thirds of previous income is guaranteed via an inflation-linked basic pension, topped up by an income-related supplementary pension, financed out of employer payroll taxes;

**health services are more equally distributed** than in other countries with relatively few people falling out of the welfare 'net', though there is great and

growing variation in municipally provided elderly care;

**high-quality 'special housing' opportunities** - including group homes, old age homes and assisted living environments - which cover around 9% of those aged over 65 years.

But there are equally several weaknesses:

a growing **needs/funding gap and a potential crisis of legitimacy**. Twin pressures of demography (many more people over 80) and a more resource-intensive long-term care model (greater emphasis on home care), combined with the funding constraints imposed by a tax-funded system lead to a danger that public expectations of care standards may not be met. Any reform takes a good deal of time to negotiate in the Swedish consensual system.

**a pressing problem with recruitment and retention of care personnel**. Long-term care is not perceived as a satisfying career option. Media reports of crises have contributed to a poor public profile for the LTC industry. Serious staff shortages are beginning to develop and will get worse as the numbers retiring increase.

**continuing frictions between counties and municipalities** over their care responsibilities, eg at the health/social service interface. For example, until recently, some nursing and residential homes refused to let doctors through the door, while doctors still are the only people empowered to discharge patients from hospital, which arguably wastes their time and others'.

## Lessons for other countries

Interesting lessons which are worth examining include:

**decentralisation of long-term care**. Local authorities have a high degree of autonomy vis-a-vis central government, with directly elected assemblies and control over the financing of their spending, ie out of locally levied taxes;

**significant policy-driven shifts in care responsibility**, including the transfer of nursing homes for the elderly to local authorities and imposing a penalty on local authorities if patients are not discharged promptly from hospital, provide useful examples for other countries;

**joint health and social services funded projects**, eg the Cedersborg project (see Best Practice Example in Section 3). These successfully combine health and social services, eg a nursing home, a short-stay and respite facility, joint assessment, occupational and rehabilitation services;

**out-of-hours services**, which are part of a strategy to enable more people to 'age in place'. In 1997, about a quarter of all users of home care services received services during evenings, at nighttime and weekends.

## **G1.2 The Strategic Framework**

### **G1.2.1 The care philosophy and framework**

The underlying philosophy of the Swedish long-term care system is one of universal provision based on the philosophy of serving all who need care equally, on the basis of a full needs assessment. The three historical pillars of this system have been economic support, housing and care. Many agents play a role in delivering care to the individual: the family, church, parish, county and central Government.

Legislation affecting long-term care has been passed since the 14<sup>th</sup> century and, in this century alone, includes laws passed in 1913, 1918, 1946, 1952, 1956 and 1982. In the 1990s, the system has undergone further significant reforms. The 1992 Adel Elderly reforms provided an updated set of aims and moved the philosophy of elderly care further away from a medical model and towards a social care model.

#### National elderly care policy aims

An extensive, long-term investigation into the needs of the aging population and new strategies was carried out at national level through the 1980s. This investigation focused on the consequences of the division of responsibility between two tiers of local government for providing health and social services respectively. After adverse media coverage of elderly care in the autumn of 1997, the Swedish Parliament decided in June 1998 on a National Action Plan for the Elderly, which came into force in 1999.

This plan agreed new policy aims for the elderly. Older persons should:

- be able to lead active lives and to influence the conduct of social affairs and their everyday living conditions;
- be able to grow old in security and with their independence preserved;
- be treated with respect;
- have access to good caring services.

An 'Action Plan' Project group has been set up, with representatives from Culture, Education, Trade and Finance Ministries and chaired by the Secretary for Planning in the Health and Social Ministry, to look at implementation and evaluation of the Action Plan. The project has three main aims: better coordination within local government (ie between counties and municipalities); improving quality in elder care and increasing recruitment of medical and social care staff. It is addressing four principal practical problems: poorly coordinated rehabilitation care, too few doctors attending municipally-run homes; problems with medication and financing issues.

#### The legislative framework

Entitlement to care is enshrined in two main pieces of legislation:



the 1982 Social Services Act, which was subsequently updated in 1998. This framework legislation emphasises the right of the individual to receive public services and help at all stages of life. It states inter alia that: "The Social Welfare Committee shall endeavour to ensure that elderly people are enabled to live independently and in secure surroundings with respect for their independence and integrity." As a result, there is an individual entitlement to assistance from the committee towards their livelihood and other aspects of living: "if their needs cannot be provided by themselves or in any other way". This right includes a right to home services and care and special housing;

the 1983 Health and Medical Services Act. This law states that health care and medical services aim to maintain a good standard of health among the entire population and to provide care on equal terms to all.

The Government has also been keen to change the attitude in society towards early retirement to and encourage people to have longer working lives in the light of an increasingly elderly population structure. There has been a vigorous debate about raising the age of retirement and the Government has instituted a major pension reform. This reform will create a much bigger incentive to work and has been phased in for those over 55 years of age.

#### The 1992 elderly (Adel) reforms

The 1992 Adel reform represented the fruition of a major effort to integrate health care and social services. As part of the national enquiry into the needs of the aging population, the Ministry of Health and Social Affairs proposed in 1989 that responsibility for the care of the elderly - political, economic and administrative - should be borne by one tier of local government - the municipality. Until the Adel reform, the administration of the system, ie the political and financial borderlines had been unclear.

The other major part of the Adel reform proposed by the Ministry was that after an elderly person was deemed fit to be discharged from hospital, the responsibility for meeting the ongoing costs of hospital care should switch from county councils to municipalities. Five working days after the discharge decision had been taken (by the doctor), municipalities would be liable for a daily charge of SKr 2,360 if the patient remained in hospital. This proposal was designed to address the problem of patients whose treatment was complete but who were waiting for services to be arranged (either a place in special housing for the elderly or for home help services) and who tended to occupy around 15% of hospital beds, and 25% of patients in metropolitan hospitals

Both these recommendations were approved by Parliament in the following year (1990). The National Board of Health and Welfare was given the task of monitoring and evaluating the reform, with a special focus on the structure, process and outcome of the reform.

As a result of this revised allocation of responsibilities, a total of SKr 20 billion was transferred from the county councils to the municipalities. In the UK a similar transfer

of responsibilities from the social security system to local authorities as a result of the 1993 Community Care Act was provided through a defined Special Transitional Grant. Post-reform, neither municipalities nor counties thought they had responsibility for rehabilitation and hence this type of care was being poorly done. The Government also decided to give local authorities an extra SKr 300 million to improve cooperation and help to provide good rehabilitation care.

The reform also provided SKr 3 billion in the form of incentive grants over a five-year period to make more housing alternatives available and to improve the quality of the housing for the elderly and disabled. The grants were used to create group living premises for the cognitively impaired, mentally ill and intellectually handicapped population. The grants were also used for nursing home alterations to increase the number of individual rooms. The objective of the reform was to maintain the functional ability and independence of the elderly by creating home-like living conditions, ie homes with a separate bedroom, toilet and kitchen, and professionals were brought in to people's own homes to provide services. There are still some residential and nursing homes of the old type, but these are in a minority now.

Since the laws mandating municipalities to take over the responsibility for the funding, organisation and provision of services for the elderly do not specify the level of services - eg the number beds in special housing, etc - the reform has reinforced the trend towards great differences in service levels and provision in different parts of the country. The Government has been particularly concerned with the horizontal inequity between municipalities in its charging policy. It is therefore introducing a bill in autumn 1999, which will impose a unified means-testing structure, a ceiling on charges and impose a minimum sum which authorities must leave clients for their own needs.

Overall, the results of the Adel reform have been patchy. There has been real change: some authorities have tried hard to improve services, hospital practices have been reformed and there are fewer shared rooms in institutional care. But there has not been as much change in medical care as was hoped, and in some areas the pattern of service delivery has not changed greatly (see Part 2 here for more discussion).

### **G1.2.2 The care model**

#### **Care assessment and planning**

The provision of care for the elderly is based on a single-entry system, run by the municipality in which potential clients live. Service input is based on a thorough assessment of care needs, carried out by a care manager, and services are allocated according to local priorities. The assessment usually starts with a home visit, or discussion with an elderly person in hospital, which reviews the request and the need for services. The family and other professionals are involved.

Multidisciplinary care planning teams are being used by more and more municipalities. Usually, needs assessment, formulation of a care package and arrangement of actual provision is done by the municipality's care manager. But in about 40% of municipalities, care is based on a purchaser-provider model. Here, the

process of assessment by the care manager is separated from the actual provision of services.

## Housing

The policy for elderly care in Sweden, as in most European countries and increasingly throughout the English speaking world, is to encourage 'aging in place', ie to support the elderly in order to prevent or postpone a move into institutional care. Since disability and dependency tend to increase with age, this policy has strong implications for housing policy. In particular, there is a need for more suitably adapted housing in which care services can be provided.

The Adel reform brought together all types of institutional elderly care under the umbrella concept of 'special housing with service and care'. This includes old age homes, nursing homes, 'service houses' (apartments with care) and group living arrangements for elderly people with cognitive deficiencies. The aim was to create a seamless system of nursing, services and care that could meet any need, irrespective of where an elderly person chose to live.

There is growing public sector acceptance of competition as a means of enhancing efficiency. Hence, local authorities are gradually operating under more market-like conditions and a growing part of tax-financed activities are now let under contract to private providers. Over 10% of institutional care (special housing) for the elderly was contracted out in 1997 compared to around 2% in 1992.

### **G1.2.3**      **Long term-care funding**

#### The breakdown of elderly care funding

Health care and social services are almost totally financed by taxes. The mix of contributions from different sources of funding varies from one service programme to another. A rough breakdown of the funding of municipality-run elderly care (ie excluding acute health care) is as follows:

<b><u>Revenue source</u></b>	<b><u>Percentage</u></b>
Local taxes	70
User charges, fees, rents & other local authority income	10
National grants	20

#### The post-reform injection of resources

The HSU 2000 Committee reported in 1996. The committee made some projections of future health care costs and came to the view that there was a future 'gap' in care funding of SKr 20 billion. The Government was initially extremely reluctant to provide the money but, spurred by regular media reports of poor standards and crises in care homes, it has allocated an additional SKr 4 billion a year of non-earmarked funding

up to 2001 to enable municipalities to carry out their new responsibilities.

However, as this is money given in the form of a block grant to municipalities (with few strings attached), this large injection of resources may not end up being spent in ways the central Government would wish. The funds look as if they will be absorbed by local government to meet a variety of calls on their funds:

the greater volume of very elderly sick people, compounded by the fact that there are fewer hospital beds to treat them in;

the additional services that they are legally charged with providing;

the increase in running costs - mainly staff costs;

servicing debts and the costs of previous mismanagement.

#### The 'bed-blocking' charge

The incentive element of the Adel reform that mandated municipalities to meet the costs incurred (at a fixed daily rate) by an elderly person in hospital when they were deemed fit to be discharged led to half of all of the people who qualified for the daily rate being discharged within 2 months. Aided by the greater availability of alternative forms of housing and care, this incentive has therefore been pretty effective in reducing the number of hospital beds occupied by the elderly who were waiting for services to be arranged in the community. Around five years after the reform, the number of beds occupied by such people has fallen from around 15% in the late 1980s to nearly 5%.

However, a study of discharges by Stockholm University showed that many people had been discharged with serious medical conditions (deep tissue wounds, etc) and some were even discharged when in a terminal state. Arguably, this shows that the incentive on municipalities may be too strong.

## **G1.3 Roles and Responsibilities of Different Agencies**

### **G1.3.1 State and local government roles**

In Sweden, responsibility for the elderly is divided between three parties. At the national level, the Parliament and the Government set out policy aims and directives through legislation and economic mechanisms. At the regional level, the 21 county councils are responsible in this context for health and medical care, ie primary care (local health centres) and hospital care at county/regional level. Around 85% of spending is on health care. Additionally, county councils are also responsible for regional transport, some education, research and culture. Finally, at the local level, the 289 municipalities are legally obliged to meet the social service and housing needs of the elderly and disabled.

The key characteristic of Sweden is the decentralisation of power to sub-national authorities. Swedish municipalities have traditionally occupied a powerful position - in law, in terms of tax-raising powers and as providers of services. They currently spend just over 25% of their budget on care for the elderly and disabled. The bulk of their income is raised locally and, commensurately, municipalities have broad responsibilities, including social services & education; housing, industry & transport; culture and recreation; electricity, water & waste as well as environmental protection. In other ways though, the Swedish long-term care system is similar to that in the UK, with responsibilities split between health (county councils) and local authorities (municipalities).

In the early 1990s cooperation between the county councils, responsible for nursing homes and home health care, and the municipalities, running residential care homes, sheltered housing and home-help services, was not very good. In 1992 the Government instituted the Adel Elderly reforms, which transferred around one-fifth of the services hitherto provided by health services to social services (in the process reducing health care spending by 1.3% of GDP). In particular, nursing homes were re-labelled from health to social services and no distinction was drawn between nursing homes and residential care homes.

### **G1.3.2 The health service**

#### **Bed closures**

One of the downsides of the elderly reforms has been the reduction in the number and power of geriatricians, as a result of the closure of long-term care beds.

As in other Western countries, long-term care beds in hospitals have been rapidly run down in the late 1980s and 1990s. Due to fiscal pressure and the introduction of the incentive on local authorities to discharge patients from hospital, counties have reduced the number of beds in short-term hospital care. Over the last five years, about 15,000 beds or over 30% of capacity in the departments of internal medicine and surgery have been closed.

### Shorter lengths of stay in hospital

The average length of stay in departments of internal medicine fell from 8 days in 1990 to 4.4 days in 1997. An even more radical effect on length of stay has been seen in the care of the elderly - the average length of stay for people with a stroke diagnosis has fallen in the Stockholm county from 56 days in 1989 to 16 days in 1993 and 7 days in 1997. This trend to bed closure and shorter lengths of stay has meant that the number of long stay geriatric beds has been halved - from around 10,000 in 1992 to around half that level (4,700) five years later. In line with the bed closure, the number of geriatricians has been radically cut.

This retrenchment occurred at a time when many in the LTC industry believed that old age had historically been over-medicalised. Before 1992, nursing homes were part of the health care industry. After the Adel reforms in the early 1990s, the involvement of doctors in institutional care was rejected by many who worked in old age and nursing homes. But primary care was as a result overstretched and insufficiently staffed. The result was that there were very sick people in long-term care homes, who were not receiving medical attention. The pendulum now appears to be swinging back and the involvement of doctors in homes is welcome again. One example of this change in view is the fact that Stockholm University is now running a 3<sup>1</sup>/<sub>4</sub>-year undergraduate social work training course, which includes medical training.

On the other hand, there is a sign that old people are over-medicalised in the sense that too many are suffering from adverse reactions as a result of multiple drug use. According to Stockholm University's research, some 20% of the elderly had drug-induced complications - mostly mild rather than severe - when their medications and symptoms were reviewed by doctors, pharmacists and researchers. This problem could be remedied by proper involvement of pharmacists in prescribing decisions and providing doctors with on-line access to expert advice. Apparently, there are doctors who are using such a system which links GP surgeries with pharmacists, but this could not be confirmed.

### **G1.3.3 The private sector**

In Sweden, private companies, co-operative associations and insurance companies are increasingly getting involved in providing long-term care and benefits. In order to set up as a service provider, they need permission from the regional court having clearly discussed their service with municipalities. The establishment of housing organisations and other organisations is still very dependent on close co-operation and discussion with municipalities, for without being seen as a credible provider it is very unlikely that a care provider would stay in business.

One of the big issues facing private providers is around contracting. The daily price for care agreed by municipalities has fluctuated significantly according to the whim of local authorities and the prevalence of scandals within long-term care. Private providers need clarity from municipalities as to what services (and standards) they require and to be sure that they in turn can meet those standards within the resources available to them.

## **G1.4 Delivery of Services and Accountability Mechanisms**

### **G1.4.1 Care services**

The fact that around 70% of women are participating in the labour market necessitates a well-developed system of formal care for the elderly. Unlike in Singapore, very few children (4%) cohabit with their elderly parents and there are no statutory requirements and incentives for children to provide care for their elderly relatives. Again, in stark contrast to many Anglo-Saxon countries with a well-embedded tradition of voluntary service, few voluntary organisations (as opposed to people) have a role as service and care providers.

Over the last 20 to 30 years, a succession of policy documents and political decisions have made it clear that care of the elderly is to be given higher priority. In the 1960s and 1970s a rapid expansion of both institutional and home care took place. This increase in home care provision relative to the size of the population came to an end at the end of the 1970s.

The clear trend over the last two decades has not been increased services, but prioritisation - usually of the care of the oldest elderly - and as in the UK, care hours are being concentrated on the most needy individuals. The current emphasis is on prioritisation of the needs of the single elderly, with married couples increasingly expected to look after themselves.

Around 160,000 people - of whom the majority (around 75%) are over 80 years old - receive home help services. This represents 11 % of the population aged over 65. About a quarter of these recipients (41,000) are more dependent and therefore also receive home nursing care. Apart from home help, there is a wide variety of other services which are provided by municipalities, including: transport, chiropody, meals on wheels, security alarms, housing adaptations and assistive devices.

### **G1.4.2 Quality assessment and accountability**

Outcomes and client satisfaction with services provided by municipalities are subject to two main checks:

elder care services are supervised by two authorities: The National Board of Health and Welfare (focusing on health care issues) and the county administrative board (focusing on social services issues). While the reports of these agencies do not have legal status, recommendations and good practice examples are usually examined and heeded;

if someone requesting services is dissatisfied with the care manager's decision, the case can be appealed in the administrative court. Although the number of appeals is very low, the right to appeal is considered as an important protection for individuals.

Operators of any kind of institutional care require a license. The National Board licenses care involving any type of medical or nursing services or care; in other cases the Administrative Board issues the license. Decisions on the number of

registered nurses per bed, the structure of care personnel or training are left entirely to municipalities. Unlike in more centrally directed systems, there is relatively little laying down of national guidelines, requirements or standards.

### **G1.4.3 Housing**

The first purposely-built housing for the elderly in Sweden - Aldersdomshem - were built in the late 1940s to provide a non-medical environment for frail and dependent elderly. The number of these homes expanded rapidly in the 1950s and 1960s until the mid-1970s. In 1991 (the last official statistics pre-merger of all forms of housing into 'special housing'), there were some 800 municipal old-age homes, providing traditional services, housing around 34,500 elderly people who were unable to cope at home even with the aid of home help and home nursing services.

Around 9 out of 10 people in Sweden over 65 years of age now live in ordinary homes, and around half of these (45%) are owner-occupiers. The general standard of housing is high, with most elderly people living in modern homes with well-equipped kitchens, hot and cold running water and an indoor toilet. However, the policy to provide care at home where possible creates a demand for home adaptations and for sufficient care and help to be available in the home when the elderly person can no longer manage on their own at home. Municipalities are responsible for arranging these types of services.

In the late 1970s, the care philosophy switched away from 'old-age' homes to 'serviced' dwellings, and government subsidies were redirected to the latter type of properties. This was not popular, however, and subsidies for old-age homes were reintroduced in 1988. In the meantime, however, many old age homes closed or were converted into 'service houses'. Rather than institutional provision, as in the old-age homes, services can be arranged according to the needs of the individual. Within such a building, services such as a restaurant, hairdresser, foot care, club rooms, occupational therapy, etc, are usually available. The key difference with the previous old-age home model is that apartments could be bought, rather than rented and the housing companies rather than the public authorities assess eligibility.

In 1991, there were 52,500 apartments in service houses and free-standing service flats in ordinary buildings. Instead of a single room of 12-14 sq metres, usually without a shower and sometimes without a toilet, serviced houses offered relatively spacious apartments (around 50 sq metres for a single) with a living room, kitchen and bathroom. The service house concept is currently the most favoured assisted living option among municipalities. In the early 1990s expansion of apartments and flats in service houses was slow, but during the last five years, private companies have come into the market to offer service houses with attached service and care. Around 10,000 apartments were due to be available by around the end of this century.

Recently, group living arrangements have developed for those who have high care and supervision needs, eg those with senile dementia. In these homes, where each resident has their own room or apartment, care is provided round the clock and care ratios are around twice that in old-age homes and four times higher (1 staff to every resident) than in the 'service house' arrangement. Group living is the most popular



and fastest expanding concept in Sweden - rising nearly 40-fold in just over 10 years from 500 places in 1985 to 5,000 in 1991 and 18,000 places in 1997.

Around 8% of those over 65 are currently in 'special', ie elderly housing, and 10% of these people share rooms. There are around 38,000 nursing home beds (sjukhem) in Sweden. The staffing density of these homes is around the same level as for group living, but the standard of accommodation in these homes is rather low, with few residents having an apartment or room of their own. The 1992 Adel Elderly reform transferred most of these (31,000) into the hands of the municipality, with the care manager or home help supervisor having referral authority. The municipalities are blurring the distinction between old-age homes and nursing homes.

## **G1.5 Issues and Policy Debates**

### **G1.5.1 How to reconcile a needs-driven system with financial constraints?**

One problem with the Swedish welfare system - including long-term care - is the heavy reliance on public funding. Only 10% of the costs are funded, while 90% are 'unfunded', on a Pay-As-You-Go basis. This implies a continuing dependence on a transfer of funds between the generations, which may not be sustainable as the ratio of workers to dependants falls.

Nevertheless, this is not the basic problem - which is about rights and access to care. Even accepting the inter-generational transfer of resources, according to a senior researcher at the National Board for Health and Welfare: "Sweden is struggling with increasing problems in securing the welfare of the elderly. Changes in the population structure mean that even maintaining present service levels is seen as more or less impossible." Tightening eligibility, greater prioritisation, means-testing and contracting out of services may make it harder for authorities to guarantee service levels. This problem is not seen as one that will go away even if the economy recovers, partly since unemployment (around 6% in mid-1999) is unlikely to fall substantially and so neither are the accompanying fiscal pressures.

Local authorities are also facing a change in the 'average' long-term care client. Originally, home care was given to people with relatively small needs, eg for home help or a few hours of personal care a week. When these clients' health status deteriorated and they needed a greater input of resources, they were typically transferred to a residential or nursing home, as appropriate, invariably in a one-way transfer. Now these clients are staying at home, are more dependent and in greater need of personal care. When they can no longer cope at home, even with significant help, they are transferred to special housing. Both at home and in special housing, these clients are receiving more intensive care.

Against this background, the National Action Plan for the Elderly was brought in to improve the effectiveness and quality of care. It had three main planks:

- a new set of policy goals towards the elderly (see philosophy of care section);
- a package of increased state block grants to local authorities to "improve the conditions in schools and caring services" (see funding section);
- a number of initiatives which sought to improve care for the elderly.

The national Government provided a three-year grant to finance initiatives and development work in particular priority areas. Among other things, this grant provided funding for the promotion of: in-service training; improved collaboration between care providers; supervision, monitoring and evaluation; research into issues faced by the elderly and quality assurance activities. Grants were also given for special housing for the elderly and, in another major initiative, SKr 300 million of state grants were given to local authorities to further develop support to carers. The National Board and Administrative Boards were also allotted special grants to extend

and increase the monitoring of the reforms as well as to strengthen and improve collaboration between the authorities.

### **G1.5.2 Has the Adel elderly reform worked?**

One of the key objectives of the Adel reform was to integrate health and social services and so it is particularly interesting from the viewpoint of this research. The approach was positive: the reform was designed to create one comprehensive 'care culture' and aimed to provide a continuum of services and care opportunities. Care personnel have been encouraged to adopt new attitudes and encourage and support the elderly to live as independently as possible.

The Adel reform tried to address a number of political, staffing, contracting and boundary problems that existed in long term-care. The reform was set against a background of strong criticism of 'traditional', especially institutional, care. Problems and attitudes which needed to be addressed included:

the view that long-term care was over-protective, over-medicalised and fostered dependency;

the poor standard of housing offered to the elderly in nursing homes, etc - few residents had rooms, cooking facilities or bathrooms of their own, which offended against the basic standard expected by Swedes;

aside from facilities, there were problems with access and quality of care. People sometimes had to move far away to get appropriate care;

the perception that care staff were poorly skilled and trained.

The overall strategic aim was to "deliver services and care to people" not "move people into services and care". It was clear that the previous model - the 'staircase' model of care, where people were moved into increasingly institutional care ('up the stairs') if their needs grew, or vice versa if they were rehabilitated, meant that around 15% to 25% of the people on any one 'step of the staircase' were assessed to be at an inappropriate level of care. The current model is therefore to replace the 'staircase' model with a continuum of care at any institution/location.

But is this asking too much adaptability from care personnel and clients?

One clear consequence of the reforms is that municipalities have had to devote more resources to the most frail and needy elderly and deal with more elderly people. Some have coped with this situation by using new finance to reorganise their care structures and allocate doctors to homes. Others, though, have coped with higher care demands by compromising the care for the less needy. One academic has commented that "some municipalities have great problems to provide service and care with an acceptable standard for residents in special housing."

The reform has taken a long time to settle down. Municipalities have had to get used to their new responsibility for nurses in the health service, new institutional provision has had to be built for people relocated out of hospital, and more income tax has had to be raised by municipalities as opposed to counties.

## Policy successes

Many of the aims have been fulfilled. Successes include:

a clearer policy framework and a successful transfer of resources into long-term care. Local authorities are more aware of their care responsibilities;

more beds or apartments for the elderly. Municipalities have used the new resources to increase elderly beds by around 10, to around 88 beds/1,000 people over 65 and 333/1,000 people over 80 years of age;

the standard of housing and care for the elderly has improved with more residents having access either to private apartments or rooms and better facilities (eg shower in their room/apartment);

more family responsibility for care of the elderly. SKr 300 million has been given to develop respite care and family support policies, which has helped to end the isolation and individualisation of the elderly.

## Problems

Inevitably, problems remain. First, the independence of municipalities means that there is a great variation in needs assessment practices and care standards, which in turn means that access to care is too random. Second, the Ministry is concerned about variations in professional standards, a lack of horizontal equity and that there is no guarantee about what services people will receive. Third, the compression in hospital lengths of stay has meant that municipalities are now also having to bear a greater part of the care required - even of advanced nursing care. This has shown up the clear need for improved discharge programmes, greater provision of rehabilitation care and better support in homes from doctors.

The area where the reforms have been least successful is in creating a new 'more social' care culture within the sphere of special housing. As the caseload has increased and those moving to special housing are now more frail and in need of round-the-clock care, municipalities have sought to bolster the medical input in nursing homes. In addition to the 'house' doctor, they have recruited more people with medical training to provide care, so as to manage the increased nursing care load in special houses for the elderly. This re-medicalisation of care - which in many respects is necessary, at least for the more severely disabled clients - has meant that less attention has been paid to stimulating the 'social life' of residents.

The 'action plan' aimed to strike a balance between resources and demands in elderly care. Some SKr 22 billion of extra resources will have been provided by 2001 compared to an increase in resources of around SKr 25 billion due to the economic recovery. The plan embodies some interesting initiatives - collaboration between providers and quality assurance activities, targeted funding and some powerful incentives, eg funding for patients in hospital post-discharge. Nevertheless, the reforms are largely a pretty conventional mixture of increased funding, strict financial incentives and firm monitoring, ie a 'carrot and stick' approach.

In conclusion, the plus points about the reform are the increased standard of housing - due largely to a significant injection of resources - and the increased proportion of skilled nurses within the pool of care personnel. While it is still true that there is still mistrust between health and social care professionals, there is now more joint working - at least with the most dependent - than before.

On the negative side, integration between medical and social services still has a long way to go - national demonstration projects, clear policy guidelines on how to integrate care for the elderly and support for integration would help here. Most commentators believe that the reforms are unlikely to 'solve' Swedish long-term care funding/provision problems, without further guidance on how to manage and develop integrated care.

### **G 1.5.3 Staffing issues**

Sweden faces some serious staffing issues. In particular, there are increasing problems of attracting care personnel. All types of professions are affected - from physicians to home helps - and the problem is not confined to rural or urban areas, but exists all over the country. Care work in general, and providing personal care for the elderly in particular, is not seen as attractive and rewarding compared to jobs in IT and commerce. The problem is due to low salaries, a series of well-publicised scandals and the perceived low status of care. Nearly everyone agrees that this is one of the most serious and pressing problems facing the long-term care system.

Second, medical support for the elderly has not functioned very well in the past in Sweden. There has been insufficient support from GPs and specialists in municipal elderly care provision, and there is a lack of rehabilitation care for the elderly.

Third, a large number of those working in old age homes and 'service houses' have no formal training at all. There is a clear need to upgrade the knowledge and skills of care personnel, as well as upgrade and revalidate existing staff skills. The elderly project team has identified a need for new training places and a commission is looking into issues concerning the working environment, salaries and working time.

### **G.1.5.4 Housing issues**

There is a tendency for there to be a growing similarity between the different forms of special housing for the elderly in terms of eligibility criteria, the standard of housing, services offered and costs for the residents. The danger here is that housing decisions could simply be based on temporal availability rather than the actual needs of elderly people. Current trends to housing homogeneity also run against cost and quality arguments that it is more effective to treat the more frailer and more medically dependent elderly in one place. Some are therefore re-advocating the provision of skilled nursing care in specialised environments.

The major problem in housing from a consumer point of view is that of insufficient service and care being available on demand. This situation is mainly due to municipalities cutting back on expansion plans in the face of financial constraints, increasing operating costs for certain types of special housing, which is in turn due to the need to increase the care staff to client care ratio.

### **G1.5.5 Future challenges**

In Sweden, there is a prevailing sense that the country is experiencing clear difficulties in adequately meeting the housing, service and care needs of the elderly. Demographic trends combined with rising care expectations and stronger financial constraints mean that difficult choices have to be made. The old Swedish solution of raising taxes to finance additional services is no longer an option since local authorities are now required by central government to keep their budget in balance.

As a result, municipalities, with tough education, child care and elderly care responsibilities, are resorting more than ever to cutbacks, increasing fees and redirecting services onto the private market in order to make ends meet. The process of care prioritisation, which the funding constraint imposes, is proving a hard one for Swedes to swallow.

The recession at the start of the 1990s affected housing programmes, too - lower government subsidies for new house-building programmes have meant a dramatic reduction in the volume of new building. This has also affected the building of new homes for the elderly and, despite state 'incentive grants', new places are not keeping pace with the need for suitable housing for the elderly.

The challenge will be to find methods - through additional funding, public/private partnerships, better staff usage patterns and models, good practice guidance, etc - to meet the unfulfilled housing needs of the elderly. Helpfully, many of the new 'old' are better off and can afford to invest in housing through the private market. Older people are also showing growing interest in new 'senior housing' concepts.

As a result of these care and housing trends, some commentators are now openly questioning whether a 'paradigm shift' is occurring in the Swedish welfare state. The fact that services are increasingly being charged for is seen as departing from the notion of a needs-based service; stricter eligibility criteria challenge the notion of universal provision and the use of contracted-out and for-profit providers is a clear move away from the norm of publicly run and provided services.

But from an international viewpoint - looking at the position in at least the English-speaking world, ie across the USA, Australasia and the UK - these trends are hardly new or shocking. It says much about the Swedish system that these issues are being faced in the late 1990s rather than the 1980s and early 1990s as they have been elsewhere. The challenge for policymakers is whether they should anticipate these changes and develop social consensus around a move to a more mixed model of welfare with greater private financing, within a predominantly public sector system or, conversely, to attempt to reverse it.

One of the remaining policy challenges is how to implement successful preventive care. The Swedes are running 20 pilot programmes in municipalities, based on a model seen in Denmark. Experience suggests that preventive programmes need to be carefully targeted and policymakers and local authorities need to understand precisely what they are trying to prevent.

## **G1.6 Best Practice Examples**

### **Example 1: Cedersborgprojectet (Norrkopina)**

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I visited several facilities for the elderly in Norrkoping in Sweden, including a day centre, a nursing home for sick elderly and people with dementia, and a housing, rehabilitation and therapy complex. The most innovative care facility that I saw was the integrated care provision in a complex called the Cedersborg project.

#### Outline of the project

This 'project' includes the following elements of care:

- outpatient care;
- a centre for short-term/intermittent and rehabilitation therapy;
- residential homes for the elderly;
- domiciliary care services.

The project has a focus on cooperation throughout the care process, including rehabilitative care. The integrated nature of the project and the rehabilitation centre are the most interesting aspects of the project. The facilities are in the process of being modernised, although the feeling is that there are not enough short-term residential care places.

The goals of the centre are primarily to increase the possibility of continued living in one's own home and thereby preventing or delaying the need for moving to a home for the elderly. Other goals are to reduce the risks of repeated hospital stays due to reduced functioning and to increase the quality of life for those living in elderly care facilities.

#### The clientele

In all, around 2,000 people a year use the entire facility, including those staying in the residential part of the project. The project is popular and probably over-subscribed. The rehabilitation centre caters for the elderly, the long-term chronically ill as well as handicapped persons with continual or long-term need for function-maintaining therapy. The largest group of clients are those recovering from a stroke, who make up 40% of the client group. The rest of the clientele are made up

of those suffering from walking and orthopaedic problems (30%), non-stroke related neurological illnesses (20%) and various other conditions (10%).

### Care process

Rehabilitation is provided on a flexible basis. Some people stay for up to 40 days in short-term accommodation above the rehab centre and receive care based on an assessment of their needs. Others are referred by GPs or are self-referred. The project has a few highly sophisticated adjustable beds, an excellent state-of-the-art OT facility with a height-adjustable kitchen and a well-used and valued swimming pool, in which physiotherapy classes are provided.

Individuals, relatives or other health care specialists are permitted to contact the Resource Centre without special consultations or 'bistand' (help) being granted. First, clients are interviewed by both an Occupational Therapist (OT) and a Physical Therapist (PT), who look at the needs of the individual. Treatment is provided only after a licensed physician has decreed that there is no medical condition contradicting therapy. Individual reviews are always done after 12 sessions to determine if further care is required.

The rehabilitation centre employs a total of 23 employees: one manager, one social worker, one relative consultant, two LPNs/receptionists, eight occupational therapists, one Occupational Therapist assistant, five physical therapists, two physical therapist assistants, and two instructors in lift and positioning techniques.

350 people a year are treated in approximately 6,000 therapy sessions. The average age of clients is 71 years of age with a spread from 31 to 92 years of age. The centre also runs individual 'Self training sessions, where people can come in for voluntary rehabilitation. About 70 people a year are served in this way, through around 1,400 sessions. The average age for this client group, as you would expect, is lower - 63 years old with a spread from 31 to 89 years of age.

### Costs

The cost of treatment is 25 Swedish Kroner (SEK) per session. There are 'bulk' discounts - 250 SEK per 12 sessions or 450 SEK for a 6-month period (only for individual/self training sessions).



## **ANNEXE 1: DEMOGRAPHIC TRENDS**

The number of people over 65 has risen from a stable figure of around 5% of the population between 1750 and 1900 to over 10% by 1950, around 17% in the early 1990s and is projected to reach nearly 25 per cent by 2020 - see the graphs attached.

Sweden is therefore one of the countries which is furthest up the 'aging curve'. The position in Sweden is therefore the future for other 'younger' countries. For example, Australia can expect to have the Swedish population structure in thirty years time. Interestingly, while other countries still have many more elderly women than men, Sweden has seen a compression of mortality between men and women due to improvements in men's and women's health and therefore commensurately fewer elderly single women.



# **THE BOUNDARIES BETWEEN HEALTH AND SOCIAL CARE FOR OLDER PEOPLE IN DEVELOPED COUNTRIES**

## **4. ISSUES & CROSS-CUTTING THEMES**

### **4.1 Introduction**

This chapter is in two separate parts, with a free-standing Executive Summary for the busy reader:

first, an **Executive Summary** provides an overview of the main findings, lessons and recommendations;

the second section looks specifically at the issues arising in connection with **Long-term Care for Older People**.

Two **Annexes** provide a thumbnail sketch of recent policy developments in the UK (Annex 1) and highlight some of the most important factors driving care costs (Annex 2).

### **4.2 Executive Summary**

This Executive Summary section of this issues chapter has three objectives:

to **look at the cross-cutting issues** arising from international experience of cross-boundary working;

to **draw out some key lessons** for policymakers, analysts and practitioners;

to **make practical recommendations for improving care** for the chronically ill and making integrated care work.

#### **4.2.1 Cross-cutting themes**

##### **Boundary issues**

Lloyd George likened reform of the House of Lords to leaping a chasm - he said the only way to do it was in one leap. In practice, constitutional reform has not proved so straightforward. Improving long-term and mental health care is similarly unlikely to be simple. **Gradualism rather than radical change is required:** a bridge needs to be built slowly across the 'chasm'.

**No country has 'solved' the health and social care boundary problem.** But some countries have softened and reorganised boundaries in interesting ways: New Zealand and Australia are running interesting **coordinated care pilots**, which pool financing for care of the dependent elderly; the US is experimenting on a big scale with **handing over the care budget direct to clients**, and the Scandinavians and Dutch have found innovative **ways to integrate housing and care**.

**There is a clear consensus that care for the very dependent elderly is best managed in a coordinated way.** This report contains evidence on how countries are trying to do this and the attendant problems. But **implementing 'coordinated care' for the most dependent older people will not banish boundary problems** within health care - let alone those existing between health care and other services. Service reorganisation, such as merging health and social care, for example, will sharpen the boundary between social services and housing. But the gains and losses from destroying old boundaries and creating new ones between different services need to be examined.

## Care issues

All countries are trying to expand or develop home care in response to the clear preferences of the elderly. Some of the evidence shows that **case managed community care experiments can postpone entry to institutional care for about two years.** The Wisconsin (USA) COP is an excellent example of an innovative intensive home care scheme. Problems implementing home-based care include: the complexity of the funding and service system (USA, Germany); restricted budgets (Sweden); overly strict administrative boundaries (Australia, New Zealand, Netherlands) and a clear shortage of community facilities (Singapore).

Discussion with experts in other countries suggests that **older people are still often inappropriately cared for in hospital.** Despite more rigorous discharge procedures, older people still tend to stay in hospital as they want the reassurance of a high-support environment and there are few alternative facilities. Further attention needs to be paid to the appropriate location of care and providing suitable packages of care in a non-acute environment. Although some US nursing homes have on-site physicians and hence are different from UK equivalents, US practice has shown that substantial downward cost substitutions are possible by providing medical care for those already in nursing homes *in situ* rather than in acute beds.

**Careful thought needs to be given to current organisational and financial incentives to remove any biases towards institutional care.**

For example, the US is now experimenting with Medicare supported hospital-at-home type schemes (which removes the financial incentive to treat people in hospital), where more technically sophisticated procedures are funded in the home environment, supported (and occasionally carried out) by informal carers.

A good interface between primary and secondary care is crucial and represents somewhat of a 'holy grail' in health care. International best practice in geriatric care stresses the **importance of starting rehabilitation and preparation for the patient's return home as soon as a person is admitted to hospital.** A rigid and sequential demarcation between acute care and rehabilitation is to be avoided. In the best care models, the **patient's GP is closely involved, and care is overseen by someone trained specifically in care for the elderly.**

## Housing issues

In order for home-based care to take place, it is clearly necessary for the older people to be living in adequate accommodation, ie housing that will continue to meet at least their basic needs as they get more dependent. This points to the **importance of providing a decent standard of social housing** and enough low-rent private sector dwellings.

The housing needs of older people will vary according to their health state. Three main categories (with further subcategories) are discernible:

- those who are healthy will be able to live in their own home with some formal or informal support. For this group, **creativity and access to low cost adaptations to enable people to stay in their own homes is crucial;**
- the frail will need support ranging from hotel and housekeeping services at the low care end of the spectrum to a fair amount of personal care and oversight at the top end. For a large number of this group, **'Assisted Living' settings could provide supportive and humane care;**
- finally, the disabled with unstable medical conditions or who are so cognitively impaired that a residential or assisted living home would not benefit them **still need specialised facilities**, eg nursing and dementia care homes.

**Coordination between housing and health or social care is particularly poor.**

The Netherlands is perhaps the most developed country in this area following an extensive post-war house building programme.

## Finance and funding

The **health care costs of aging are unlikely to be a major source of fiscal pressure in the next 20 to 30 years** in most of the countries examined.

Inappropriate use of services and unnecessarily costly or acute care settings are likely to be a greater concern for policymakers and funders.

International and academic **evidence warns against an over-optimistic view that integration initiatives will self-fund new services through 'savings'**. As integration projects move beyond the demonstration stage, policymakers must also think about earmarking funds for their continuation - from within existing resources if necessary (forcing economies elsewhere) - so that the benefits of the projects are not foregone in the face of routine funding constraints.

**The arguments for risk-pooling in long-term care are persuasive.** The challenge is to find acceptable ways for people to access the wealth locked up in their assets (homes, pension funds, etc) and use the monies released to complement existing public funding.

Few people believe that a single budget within one department or organisation is the only answer to high quality long-term care. But **pooling care budgets, coupled with a separation of assessment, care package formulation and service delivery, is more cost-effective and can achieve higher quality care than joint service planning and delivery on its own.**

**Direct payments are being looked at in many countries and are, overall, a positive model.** The interpersonal and other benefits of receiving services from a family member seemed to outweigh any possible shortcomings in technical skills. Problems which need watching include the deadweight cost of remunerating previously unpaid family labour, effects on the existing community services infrastructure (effects will be different in systems with well-developed and poorly developed formal care services) and the possibility of funds being misused.

The effects arising from perverse incentives and poorly designed systems can be extremely costly, eg in pushing people into nursing home care, as in the British case from the mid-1980s to mid-1990s when costs escalated from £350 million to £2.5 billion. In contrast, **getting incentives right can save greatly on costs** - of the incentive in the German long-term care insurance scheme to take cash over formal care has reduced welfare assistance payments by an estimated DM10 billion.

**There is an urgent need to move beyond funding outputs, which reward one activity over another, to person-centred outcome-based funding models.** Most systems still specify the achievement of outputs, and satisfactory outcome measures are hard to create. Best practice is for the client to discuss and agree outcome-based goals and measures to assess progress against relevant goals.

### **Implications for UK long-term care services**

A key question is: **Is further structural change required?** At a strategic level, the UK's policy orientation towards home-based care (post 1993 Community Care Act) and encouragement of coordination fits well with the international consensus on providing coordinated care at home where possible. UK policy is well articulated, reflecting a powerful 'centre' and resulting in some of the best developed policy, eg on care management in the developed world. However, this does not always translate well into practice on the ground.

The major **distinctive area of weakness for the UK is the financial borderline between health and social services.** Introducing more charging or means-testing into the NHS (probably the preferred Treasury option) would renege on a key, and politically very popular, principle of the NHS. However, expanding the services provided free at the point of use by the health service (the Department of Health's preferred approach) would be potentially pretty costly and do little to improve quality - a key commitment of ministers.

There is also **no easy solution to the current organisational boundary.** Major changes to the way long-term care is organised would be extremely disruptive, unpopular and would create fresh and equally intractable boundary problems. The Swedish reforms, which blurred the boundary between health and social care, arguably worsened the acute LTC boundary. **Improving the co-terminosity of county, borough council, primary care and health authority boundaries would enable social workers and nurses to service the same area.** Two options seem worth exploring, perhaps through pilots:

**encouraging primary care groups to organise coordinated care** or jointly

commission care with local authorities;

**enhancing local government's role in organising and managing long-term care**, eg through passing control and responsibility for community nursing and rehabilitation to social services departments.

#### **4.2.2 Chronic care: the lessons from international practice**

##### **The need to distinguish linked/coordinated care and full integration**

There is a big difference between better-linked services and care coordination on the one hand and fully integrated service provision on the other hand. **Only a very small minority of the elderly will need fully integrated care.** Less than 5% of the older people are likely to have the complex, multiple, chronic health care needs which benefit most from integrated care provision. **Access to such care needs to be carefully screened** to contain costs and deliver appropriate care.

##### **A recipe for successful integration**

Successful integration requires goodwill and measures to address the cultural differences in how different professional groups work on the ground. It also requires **a single assessment form to record clients needs; integrated clinical and management information systems and proper attention given to staff training from the outset.** Failure to increase training budgets for staff in new coordinated care operations has frustrated many integration efforts.

##### **Involving primary care doctors: A double-edged sword**

Physicians or **general practitioners (GPs) are central to well-functioning cross-boundary chronic care provision.** Nowhere in the world was coordinated care happening well without their active involvement and patients clearly benefited from, and felt reassured by, GP engagement. Cumbersome referral practices between GPs and social service departments need to be streamlined.

However, experience suggests that **GPs generally make poor care coordinators** since they already have heavy medical caseloads and understandably often lack appropriate administrative skills. There is evidence that much 'good practice' is designed to minimise the intervention, or effect on, GPs. In fee-for-service systems, and perhaps to a limited extent in publicly funded systems like the UK, payments for *specific and specified* coordination activities may help to improve coordination in practice.

##### **Importance of piloting with follow-through**

The US, Australian and New Zealand **experience demonstrates the value of properly run pilot projects.** A good catchment population for an integrated care pilot could be between 250,000 and 500,000 people (equivalent to a small county or a large city council).

The pilot would need to be carefully set up, properly resourced, thoroughly evaluated

and embody a commitment to mainstreaming the pilot if it was deemed to be producing useful outcomes. In the USA, many good initiatives never get rolled out to the general population, primarily due to the vagaries of the political system. This fate is to be avoided if at all possible.

#### **4.2.3 Policy ideas and examples of good practice**

##### **Areas where the UK can learn from abroad**

There are some particular areas, for example better links between the hospital and the community, reducing inappropriate stays in hospital and providing more flexible housing options, where the UK can clearly learn from other countries. Other examples are:

sound public health policies and upstream **prevention activities are the bedrock on which a viable long-term care system must be built.** Positive international examples of successful prevention measures include local information/advice centres in Germany, US HMO health checks and self-help manuals and Swedish comprehensive domiciliary care networks/primary care centres. The UK could build on the links established with patients through 'NHS Direct' to provide pro-active ill-health prevention advice;

**the role of geriatricians is stronger in other countries.** Like many ideas invented and exported by the UK, geriatricians now play a more important role in other countries (eg Australia) than they do in UK care practices. The health care problems of older people are particularly complex and often specific to that population. Evidence shows that geriatrician-led programmes are usually more public-health oriented and (working closely with the client's GP) provide a more comprehensive health care for elderly clients. We have much to learn from systems which link secondary care (geriatric medicine and old age psychiatry) better to community care;

**multidisciplinary is better than mono-disciplinary assessment** In the UK, for the most part needs are assessed by social workers. For people with ongoing needs, multidisciplinary assessment - involving nurses and social workers - helps to identify all the client's needs at the outset and avoids the costly and time-consuming problems arising from unseen and unexpected complexity at a later stage in treatment;

The housing choice facing elderly people in the UK is unnecessarily limited. A **wider choice of housing options is necessary** to help people make the transition between hospital, a nursing home and their own home. US and continental assisted living and shelter-with-care options need to be studied and implemented where possible;

**integration of funding would help** to deliver more integrated care services on the ground. The UK borderline between privately paid and means-tested social services and a health service that is free at the point of use is unhelpful. Creative options for charging, co-payment and direct payments, in return for guaranteed access to services, could be explored



## **Areas where the UK can build on its own good practice**

**capacity needs to be built in to the community to enable people to help themselves.** Health action zones in the UK are doing some very interesting work in encouraging individuals from deprived communities to take more active roles in the community. A big stumbling block is the benefit system which still makes it difficult for people to combine work and other interests. In long-term care, international evidence supports the view that respite care has a crucial role to play in allowing people to preserve their autonomy;

### **NHS Trusts and local authorities could become better purchasers.**

Besides capitated funding and comprehensive care assessment, delivery and funding structures, it is vital to help consumers become informed purchasers of health and social care. Organisations like the Audit Commission in the UK and the Foundation for Accountability in Oregon in the USA are doing a lot of useful work in this area;

**build on successful initiatives by incorporating monies into mainstream funding.** There are examples where 'winter pressures' money has been used very constructively to address structural issues, eg through funding joint teams for care for the elderly. The benefit of this funding will be lost if it is not incorporated into recurring funding;

**wasteful structures and practices could be reduced.** The UK has cut average hospital lengths of stay markedly in the last 10 years. But this could probably be cut still further - perhaps by as much as 20% in the short run. More attention could be given to reducing over-medication and the duplication of care by different professionals.

## 4.3 Care and Service Models

### 4.3.1 Person-centred care: 'horizontal' vs 'vertical' care delivery systems

Reassuringly, but perhaps not surprisingly, there is a clear international consensus that care in a person's own home, or in the community, is the preferred setting in which to provide long-term care. This orientation fits in well with the UK's policy setting which has favoured home-based care since the Community Care Act was passed in 1993. It also accords with more recent 'triage' models of care in the NHS, where the aim is to minimise unnecessary treatments and ensure patients are treated in the lowest cost setting, consistent with them receiving high quality care.

Besides broad agreement in all the countries visited that home-based care is preferable to institutional care, there is an international consensus that care of the very frail or disabled elderly is best managed in a coordinated way. The main reason for this is that such older people tend to have *multiple, interrelated and often complex health needs* which people recognise need to be treated holistically.

While survival to older ages in industrialised societies today is rightly recognised as a 'success story', an aspect of treating people holistically is to recognise that the quality of life for older people, measured by their ability to function well and play an active part in their social group and society, is a more important health care focus than length of life per se.

The key concept here is disability-free life expectancy (DFLE). Recent American research shows that the increase in DFLE in the USA between 1980 and 1990 was due to improvements in education, housing, the labour market and socio-economic circumstances, as well as health advances. But health care may not be the most important determinant of increases or reductions in DFLE.

Person-centred care is a vital ingredient in all good care systems and can impact importantly on quality of life. While most policy documents pay lip service to this principle, few countries implement it consistently and successfully. In order to implement person-centred care, service delivery needs to move out of 'vertically' administered *organisations* which provide services, such as hospitals, social services departments, schools or housing agencies and towards 'horizontal' or virtual care *networks* (eg primary care networks and HAZ bodies in the UK).

Throughout this century, 'vertical' care organisations like hospitals have generated great health gains and positive 'externalities' in an economic sense (gains to other members of society as a result of services delivered to one individual). But on the eve of the 21<sup>st</sup> century these hierarchical and bureaucratic forms of service delivery look as if they have reached their limit in terms of delivering better care to clients. The greater complexity of needs, diseconomies of scope, and modern medicine's ability to treat ever more dependent clients in less formal settings (eg through drug therapy) mean that the costs of organisational friction resulting from several 'vertical' agencies interacting imperfectly may be beginning to outweigh the clear benefits in terms of care.

But to say this baldly might be to oversimplify and perhaps overstate the case. The debate can be characterised as the extent to which organisational and financial integration is needed to achieve service integration. You can have the latter without the former. Making person-centred care work does not *necessarily* imply creating new forms of organisations. Several less radical approaches exist:

first, the boundaries of the vertical organisations could be blurred, eg through shared care protocols at the caseworker/care-delivery level;

second, in practice the way services are delivered and boundaries need not be the same for all users even within current 'vertical' delivery models - the severely handicapped are usually treated differently from the moderately or mildly impaired, eg US PACE programmes;

thirdly, it is important to keep the focus on improving outcomes and lowering costs through better use of resources and improved methods and styles of intervention.

The UK and other countries are already pursuing all these approaches and there is probably quite a lot of 'mileage' still to be obtained from 'vertical' systems in this regard. Whichever structure is chosen, the way that people are deployed, resourced and managed is ultimately the crucial factor. The model that provides the best outcomes is likely to be a product of the commitment given by the key players, the assumptions and understandings reached by them, the power of professional groups and the liberation of the energy of adaptable people.

Even though existing policy can nearly always be better-implemented and more effort can be brought to bear to make new policy work - eg on pooled budgets in the UK - more fundamental changes may be necessary to help those "trapped in the chasm between the incompatible principles of health and community financing" (Davies, *Thinking Long in Community Care*, PSSRU). Options for structural change can be thought of in (at least) two dimensions:

organisational change. This could encompass a broader role for local authorities or the NHS, enabling a wider range of social and health care services to be provided through a single point-of-entry service. Such a service would be set up to provide integrated care - an example of today's notion of a 'one-stop shop' - with more specialist teams available for some key cases at some crucial points, eg stroke discharge;

financial regime change to create a new funding mechanism. This could include the creation of risk-pooling insurance mechanisms for people not eligible for state low income benefits, new financing which enables people to access the wealth locked up in their housing or the further encouragement of public/private funding partnerships, eg to develop home-based care.

Policymakers have already toyed with and implemented limited reforms in both of these areas, eg encouraging collaboration and shared protocols, permitting pooled budgets and exploring the idea of US-style long-term care insurance arrangements. But, as is argued in the later section of this chapter dealing with the implications of

international examples for the UK, these fall short of resolving the fundamental boundary problem caused by the different financial regimes applied to health and social services.

### A typography of care

What are the practicalities and modalities of providing care? As explained below, individuals will need different patterns and levels of care depending on how fit, frail or disabled they are. These might be characterised in three main groups:

- 1) an 'AA' (road safety, not alcoholics anonymous!) model of care for the bulk of the over 65 population who are essentially fit, but require occasional spells of acute care. These mainly 'young' elderly will benefit from prevention measures and holistic care;
- 2) an 'ACAT' (aged care assessment team) multidisciplinary intervention model for those who are frail and have perhaps 1 or 2 on-going chronic conditions, which may become more severe and/or frequent over time. These clients require coordinated care;
- 3) an 'ER' (emergency room) care model for those who are disabled with multiple, complex, severe chronic conditions. These individuals will require fully integrated care.

Leutz in a recent analysis of health and social care services in the US and UK (Leutz N, *Five Lessons for Integrating Medical and Social Services: Lessons from the US and UK, Millbank Quarterly, 1999, No 1*) cogently describes a similar typography with the following care levels and associated systems:

Linkage - practitioners try to form links with each other, know each others' services and share relevant client information when necessary. At best, this implies integration at the level of practitioners, eg an individual GP. Good practitioners probably do this already. Leutz remarks that clients for whom this care model works well are those with low/moderate disabilities, whose needs are relatively stable and who are self-directed. This corresponds to my level (i) above;

Coordination - systems of care still operate independently but "explicit structures and individual managers are installed to coordinate benefits and care across acute and other systems" (Leutz, op cit). Clients who will benefit from this level of care have moderate/severe levels of disability, are stable and need a moderate to broad range of services and might be able to self-manage. This corresponds with the model described in (ii) above;

Full integration - new programmes or units are created. Funds are pooled from multiple systems to create an integrated care programme, which is managed by a team or 'super' case manager. The team accesses a common client record. Clients receiving this level of care are those who are at the moderate/severe end of the spectrum, have difficulty managing the broad range of services required and whose condition is on-going, unstable and

necessitates sometimes urgent interventions. This corresponds to model (iii).

We are mainly concerned here with the more complex and challenging models of coordinated or integrated care, rather than the 'linkage model', although the latter can be seen as complementary to, and perhaps a step on the road towards, more coordinated care. In Leutz's framework, 'linkage' clients need little in the way of coordination: "a critical difference [between linkage and coordination]... is that, when urgent or complex circumstances arise, there are systems and personal relationships in place to identify changes and ensure coordination ... Full integration is probably appropriate only for a small subset of each group of persons with disabilities."

The Social HMO sites in the US have generally operated at the 'linkage' and 'coordination' levels of integration, while the PACE projects and 'Community Options' type experiments are examples of full integration (see US chapter for more details). UK mainstream practice has hitherto been more at the 'linkage' level, though the Kent and other case management experiments have operated at the 'coordination' level.

Whatever model is chosen, though, it is a fallacy to believe that implementing 'coordinated care' will at a step banish the boundary problem. Practical experience and thought shows that boundaries will still exist, eg between coordinated and uncoordinated services, and new boundaries will be created, say between joint health/social services and housing or transport.

#### **4.3.2 International coordinated and integrated care**

Coordination means different things to different people. It can signify anything from closer coordination of care for individuals through to an integrated care model run through a single provider or a managed care organisation (MCO) that either owns or contracts for a wide range of medical and social services.

As if lack of agreement over the nature of the model is not enough, Leutz points out that there is little consensus about who should be the case manager in charge of integration, client groups to be targeted and what organisational and supportive structures are needed. These questions are explored in turn below.

##### **Who should be the case manager?**

Irrespective of the model chosen, a variety of coordinators can be envisaged since the care coordination function can be carried out by different agencies. There are three different options for who carries out the actual care coordination function: first, where the primary care physician (GP) is care coordinator; second, the GP coordinates care but is supported by a service coordinator; third, an independent (non-GP) coordinates care and the GP assists with developing the care plan.

Most commentators and those who have been involved in 'community options' type experiments are of the view that care coordinators need to be independent of existing institutional structures. The Australian evidence (see below and Australian chapter for more details), for example, does not support the view that GPs make the best, most efficient or most effective coordinators, although in any event Australian

GPs do not have the gatekeeping role of UK GPs. Intuitively, GPs are medical practitioners and cannot be *expected to* have the skills required to coordinate different service streams, including their own, although they may in practice have some of those skills.

#### Which client groups should be targeted?

It is vital to focus on who exactly will benefit from care coordination and use that information to design entry criteria. It is advisable to frame the catchment population so that it contains a mix of clients including those who are likely to benefit as they have under-met needs and clients whose health is likely to improve and thereby to generate savings. Recruitment criteria need to be flexible and exit criteria must be clear (including the dimensions of cost, economic and health/well-being) if care coordination has a limited budget. An 'outlier' policy also needs to be framed to cover high cost clients.

Clients need to be carefully classified so that the right intensity of services can be provided as well as for capitation purposes. Characteristics such as expected care coordination needs, complexity of needs, opportunity to generate savings, total historic needs, availability of carers, previous and future risk of hospitalisation need to be ascertained and evaluated.

#### What supportive structures are needed? - Coordination models

There is a hierarchy of coordination models, which broadly follow the linkage - coordination - integration typography outlined earlier. These different models for integrated care focus respectively on service provision, organisational structure and finance, though all three inevitably impinge on each other and interact in practice:

- Level 1:       **coordination of services** through encouraging joint working and implementing shared care protocols;
- Level 2:       **integration of provision** through merging service providers and allowing a single organisation to provide services hitherto provided by a variety of different providers;
- Level 3:       **integration of finances** preferably through a single budget, though pooled or shared budgeting is a weaker version of this model.

Until recently, UK policy has focused on the Level 1 approach with policy characterised by an encouraging providers to work together. This was primarily an exhortatory, approach, though a variety of pilots have been put in place to provide resources for coordinated care. Northern Ireland is an example of a country that has gone down the Level 2 route by combining health and social service authorities. Many countries, including the USA, Australia and New Zealand as prominent examples have experimented - at a trial level only so far - with financial integration.

Two types of coordination are worth exploring: the 'Continuum of care' and 'Community Options Programme' models. It is tempting to think that a 'step-down' or 'continuum' model provides the answer, as it encompasses a variety of support

arrangements which are likely to be needed at any point in someone's life and people typically move from less to more dependent states. The model assumes a passage over time from less restrictive to more restrictive and more regimented service environments as disability increases. However, the concept of moving from home to apartment, to sheltered living arrangement, to foster or boarding home, to nursing home has lost its appeal on purely practical grounds as older people do not want unnecessary transitions.

It also often fits uncomfortably with the notion of 'choice'. To have a 'choice' of care in a 'continuum' approach usually meant having a choice among several institutions, where perceived quality, location, price and any religious affiliation are the main criteria for consumer selection. But as occupancy rates increase and waiting lists develop, choices of sheltered provision and nursing homes tend to become more limited. Arguably, the most important long-term care choice is the choice of whether to receive care in or outside an institution. For this choice to be a reality, the necessary combination of formal and informal services must be available in the setting preferred by the client.

In most countries, the 'aging in place' concept has come to assume prominence. In this model, services and supports are organised around the individual in the place they have chosen to live throughout their old age. Within this paradigm, the Wisconsin 'community options' approach seeks to give a targeted number of individual elderly and disabled persons choice about their long-term support. It requires the development over time of a range of service options and a variety of providers so that consumers can find assistance which is appropriate and fits their personal needs and preferences.

Beyond the provision of a range of formal, and importantly, informal services, the 'community options' approach is intended to empower the consumer to exercise the right to choose where and how to receive long-term support. It requires a relationship between the client/consumer and 'helping person' - case manager - so that the latter can provide the older person with full information through assessments and care plans about the kind of help they are likely to need to stay in the community and how that help can be organised and paid for. Above these practical considerations lies a vision of communities in which the very old/disabled continue to be embraced as part of the community, a neighbourhood and family.

#### A practical example of 'horizontal' care - the Australian Coordinated Care Trials

Examples of coordinated care are in place and operating in most developed countries. I will use here the example of the Australian and New Zealand Coordinated Care Trials as these are distinguished by being relatively large in size (compared for example to US PACE projects), well developed and rigorously evaluated. These trials provide an example of an attempt to provide coordinated and community-based care in the place of vertically delivered and institutional care (see the Australian & New Zealand Chapters for specific trial-level details).

In the trials, one local organisation is appointed to run the trial and provide clients with all aspects of care from assessment, a care package, rehabilitation and, if necessary, residential or respite services. Each local patient has a case manager.

The Commonwealth-funded pilot projects involve pooling funds previously allocated to different departments and providers.

The trials are providing the opportunity to test:

the **pooling of funds** across a range of funders and services. The trials are testing whether fund pooling, by changing the relative prices between health and social care providers and allowing flexible provision and substitution of home-based for formal residential services, can lead to cost savings;

the **pooling of provider resources**. Providers generally have poor links, whether intra-service or between services, and are unaware of the availability of services of other providers. Staff resources are not deployed to optimum benefit - a more expensive professional is often given tasks that a less experienced or less trained person can perform adequately;

the **alignment of decision-making** across all the needs of one client and the needs of a group of clients. This implies a consistency of screening - ideally, one screening tool - and inevitably involves the co-operation of care managers, coordinators and GPs. The trials have chosen different types of care coordinators and levels of coordination. The aim here is to improve allocative efficiency across clients and enable preventive and public health interventions to be prioritised;

the **collection of client-based and intervention data**. Coordinated care enables a detailed database on clients to be kept in one location, irrespective of their location. This data collection allows providers to select clients who might benefit from a particular type of intervention (eg fall prevention).

The early evaluation seems to show that there are two main issues:

cost reduction. Can the trials create savings - by preventing hospitalisation and/or reducing lengths of stay - in order to pay for additional community care services or care coordination costs?

service enhancement. Do the trials change the way services are provided either through delivering a better mix of services at the same cost or provide more effective, and possibly lower cost, services by changing the methods used by agencies to deliver services?

### Outcome and lessons

It seems that most of the trials which included Home & Community Care services achieved these goals to some extent. The trials are due to conclude in spring 2000, and therefore the 'jury is still out' on the model's cost-effectiveness. The main concerns are about the extra costs of administration (particularly the cost of care planners) and the cost of satisfying of previously unmet needs, which have been recommended by care planners.

Evidence from projects which have pooled funding, eg PACE projects in the USA,



geriatrician-led care experiments in New Zealand and Australian coordinated care trials has also yet to be properly evaluated. It therefore has yet to be proved that the costs of setting up the care coordination machinery and working round the new boundaries created will be outweighed by the benefits from lower service use, eg hospitalisation, GP visits and drug intake.

The Australian trial evaluation (*Major Interim National Evaluation Report on the Coordinated Care Trials*, KPMG, June 1999) has some insights into the future developments and replication of coordinated care in other countries:

first, the criteria for client access/usage needs to be carefully defined in terms of complex and chronic needs. It is important to think carefully about how the operational process works. A tight rein needs to be kept on GPs or other care providers, who want their clients to have access to coordinated care;

second, thought must be given to the capitation rate used to calculate fund pools. Experience suggests that a variety of rates be used to reflect the range of risk and utilisation represented by clients. One capitation rate per service is inadequate;

third, it is important that there is a broad pooling of services. In particular, community services should be included alongside health services such as primary and secondary (hospital) care and drugs budgets;

fourth, data must be accessible and shared between providers.

A wide variety of other thoughts and lessons have been provoked by the trials including timing issues; the client base, client classification and management; financial design and identification of costs; administration costs; information collection and training.

Timing issues. In implementing coordinated care, policymakers, practitioners and evaluators need to maintain a longer-term focus. For example, it is very unlikely that interventions to delay or prevent hospitalisation are likely to show benefits over a short time horizon such as 1 to 3 years. Similarly, start-up costs are unlikely to be 'repaid' in a year or two, although the average cost per client day will fall as time passes and people get more expert at new ways of working. It is important to avoid the short-termism present, for example, in the commercial world, where managers can have unrealistic expectations of how soon an investment can 'pay off'.

It is also advisable to proceed with coordinated care carefully and in stages, given the steep learning curve of participants and the inevitable challenge to existing power structures and ways of doing things. A few well-run pilots may well be beneficial in the long run, provided that there is a clear commitment to implement the scheme if the results are favourable. In the USA, too, many interesting innovations are bypassed because the executive has changed, the legislative 'window' has gone or a new policy fashion has taken hold.

Financial design and identification of costs. Care needs to be given to the approach used for evaluating the financial success of the trials. In the Australian trials, it has

proved difficult/costly to derive an estimate of costs that would otherwise have been incurred and to prove that hospital usage has been reduced. Using data collected from coordinated care pilots over time in conjunction with historic data from existing clients may prove more fruitful. Better identification of the economic full costs - to the health system and consumers - reduces the risk of cost shifting and risks of managing pooled funds. Examples of costs that need to be identified and the funder agreed include: the costs of negotiation and monitoring; out-of-pocket costs incurred by clients and the costs of non-pooled services that were provided to, or purchased by, clients.

Fund pooling should be restricted to services where there is a straightforward cost estimation and comparison process, transaction costs of accessing the pool are small (or care items are large) and the capacity to effect change through the fund pool is significant. Consideration should be given to using block grants to substitute portions of the fund pool where the costs of pooling funds (time and transaction costs) is likely to be greater than the benefits. The design and impact of financial incentives to use or not use certain services (eg residential care) needs to be carefully thought through.

Administration costs, information and staff training. Experiments in coordinated care need to define and set a benchmark for set-up, management, administration and evaluation costs. These averaged out at between 23% and 45% in the Australian trials - pretty high even for 'trial' situations.

Improved quality of data from hospitals and domiciliary care agencies will be necessary if coordinated care is to work well and staff training needs to be thought about before a new care pattern is instituted. Any attempt to reduce administrative costs for mainstream services should be considered very carefully before requiring savings in this area from integrated care projects. These projects would be better ring-fenced, at least until they are established.

Is coordinated care better for all elderly clients?

Almost certainly not. There is little evidence that coordinating care for all elderly would be more cost-effective than simply better collaboration, and there is no evidence so far that it would improve outcomes for all. If coordinated care arrangements preempted resources, they might even conceivably worsen outcomes. The elderly are not homogenous, and it is likely that some (very dependent) elderly are likely to benefit far more than others from formal coordination. Medical instability, and consequential possible deterioration in health status, is likely to be a critical factor in deciding to provide integrated care.

It may help to think of the elderly in three broad groups - the fit, the frail and the severely disabled (see diagram below). Most elderly people - perhaps around 75% of the over 65s (and around two-thirds of those over 70 years old) have either no disabling conditions or only a minor handicap. They, like other members of the public may have acute care needs, and these *may* result in the need for structured or ongoing care, but these care needs will be episodic. These can be categorised as the 'fit elderly'. Policy towards these older persons can best focus on self-care and prevention.

Progressive American care organisations and HMOs have demonstrated some useful techniques and approaches here. For example, the 'fit' elderly might be encouraged to generally self-care and treat and pay for minor (non-operative) conditions through over-the-counter drugs, alternative therapies, etc. Major unexpected acute care would continue to be provided free at the point of use through the public health system as now.

A further 20% of the population of over 65s typically use some in-home support services and may have one or two chronic conditions which will require on-going care, probably coordinated by the person's GP or family doctor. Such people can benefit from proper assessment of their needs (as through the Australian Aged Care Assessment Team Model or UK Community Care approach) and brokerage of the resulting care services. It is for the 'frail elderly' that a substitution towards home-based care could be most relevant and potentially save costs (though costs would not necessarily be less in all, or even most, cases).

It is for the 'disabled elderly' - perhaps 5% of the population with multiple, chronic conditions and complex health care needs - that coordination of services is likely to be most useful, positive in terms of outcomes and quality of life and cost-effective. However, even with this group, good protocols and improved shared practice arrangements and understandings may go a long way to improve care. Some of these - the most chronically ill - may be more cheaply and effectively treated in a dedicated care environment. However, even with these groups, there is evidence from Australian (eg Victoria State's Mental Health Plan) and US practice that very disabled people can be successfully cared for at home, provided round-the-clock care is not required and community facilities and support networks exist.

### **4.3.3 The health/social care divide**

Two questions that often lurk behind any discussion of integrated care are, first, which agency or setting is the right place to coordinate care, eg ACATs in Australia or a not-for-profit institution and, second, which staff should act as the care coordinator - health, social services or an independent party? No one service provider is uniquely able to perform a service coordination role. Various providers who provide important parts of the care chain could in practice integrate or coordinate the care given by other providers. It is important that where multidisciplinary care is provided, accountability arrangements are still maintained.

In most countries, the (acute) health service still has the upper hand and is usually better resourced. However, experience abroad suggests that a 'cure' model - overly focused on acute care - is not always of maximum benefit to care recipients. If the health care system is given responsibility, as for example in New Zealand's Elder Care Canterbury Project (see Best Practice section in the New Zealand chapter for details), then it is important that someone whose training ensures that s/he looks at the clients's overall functioning in a family and community context is in overall charge of the care from assessment to discharge. A geriatrician is an excellent person to fill that role, though others could do it, too. Regrettably it seems that in many countries, including the UK, the training of geriatricians is not a high priority today for health care administrators.

One of the clear lessons from other countries' care systems is that everywhere family doctors (GPs) play a crucial role in assessing, arranging and providing medical care. They are a vital 'cog' in the system: often, they are the first port of call for people when they are sick, and the degree of trust placed in a GP by a client has important implications for the outcome of care. It is therefore important that care coordinators work in a collaborative way with family doctors (GPs). This needs to be handled carefully and may require a good deal of local discussion. If primary and secondary care providers are not liaising well, as has been the case in New Zealand and can be the case in the US for some patients, then care needs tend to go unmet.

All coordinated care trials acknowledge the centrality of the GP in the provision of quality primary care and the important contribution they can make to the care planning process. However, the Australian and New Zealand coordinated care experiments have revealed that involving GPs in coordinated care arrangements is not unproblematic. First, the trust of GPs has to be won over, as they may believe that the appointment of care coordinators is an attempt to usurp their role as guardians of their patient's health. Inevitably, given a person's complex configuration of health, social and personal health, this is an overstatement of their role, especially given the increasingly limited time GPs have to address patients' concerns (nurse delegation can be useful in this context) but it is a reality that planners need to face.

Second, care coordination means that GPs will have to carry an additional set of responsibilities, adding pressure to an already busy practice routine. For many GPs, with the other issues and reforms that are already occurring in their practice, coordination will place an excessive additional demand on their time. Unless GPs are providing coordinated care for all their patients, which is unlikely, they will be required to act differently for a subset of their patients. This adds complexity.

The Australian experience shows that if GPs are given responsibility for coordinating care, they perform this task variably. After a good deal of discussion in the Care 21 trial, most GPs are now supportive of the project and actively participating in the trial. However, in another Australian trial, most GPs have not performed their coordinating task well. This is perhaps understandable since GPs are medically trained and have not hitherto, with some exceptions, seen their role as coordinating all the different pieces in the care jigsaw.

The best outcome may be where there is an effective relationship between the service or care coordinator and the GP, who is structurally positioned to make a central contribution to the integration of care of chronically-ill clients, but is freed of the administrative tasks of actually coordinating care, with the inevitable 'paperwork' this task entails. Explicit payment to GPs for care planning and inter-professional case discussion may help smooth this process and provide the necessary financial recognition of the time spent by GPs in these important integration activities.

If care is decentralised to social care agencies and community providers, as in Australia (due to different state traditions and accident!) and the USA, then it is best if a care manager within *one agency* is given the task of coordinating health and social care, and this person is able to access a broad range of different funds. In countries studied (eg Australia), such managers came from a wide variety of

backgrounds and disciplines. Care coordinators can be located in a wide variety of locations, though it is desirable that the location be seen as a community resource. Community (Health) Centres may be an example of such a location, provided they were not associated with a particular service. Alternatively, care coordinators could work out of GP surgeries or social services offices using a dedicated office or laptop computers.

#### The problem of 'turf-protection'

Turf-protection, concerning the roles of agencies and control over their own finances, is a significant issue when coordinated care is attempted. Agencies are often unwilling to contribute 'their' funds to a pool, with the potential loss of control and the possible impact on the organisation's internal financial position this might imply. Experience shows that the smaller the difference between the coordinated care process and the status quo, the greater the conflict between participants in coordinated care is likely to be. The status of the care coordinator (statutory, budget holding or negotiated) is likely to affect their perceived legitimacy.

In the South Australian 'HealthPlus' coordinated care trial, coordinated care was seen by some (presumably in the hospital sector) as involving "a loss of control over referrals, increased workload and a lack of extra resources." Hospitals are often the most jealous guardians of their power and funding. A quote about fund pooling taken from the same trial is illustrative:

"... it is funding that is taken away from hospitals ... surely some of it comes back, but if hospitals are under-funded to begin with, it's *seen* as an extra impost. If the funding came from a separate pool of money, I think there would be a lot more enthusiasm and acceptance at the hospital level for coordinated care." (my italics)

Common sense (or realpolitik) states that unless hospitals and social service departments are compelled by strong financial or policy controls - or lured by new funding - they are likely to hold on to the control of their services and thus their jobs. Even if compelled to develop new models, inadequate training is likely to take place unless funds are specifically earmarked for this purpose. Since coordination requires more attention, training and cooperation from more people, inadequate thought and resources devoted to these areas is likely to jeopardise the projects themselves.

#### 4.3.4 Housing and care

##### **Organisational separation of housing and care provision**

In some of the best practice seen elsewhere in the world (eg the Partnership programme in Wisconsin, Humanitas in the Netherlands, Mercy Family Care in Australia and the Martin Luther Stiftung in Germany), the provision of housing services - apartments and sheltered housing, etc - has been functionally, but not organisationally, separated from the delivery of care. Housing and care may often be provided in one place or even under the auspices of one organisation, but the two need not be jointly provided: housing and care are often actually carried out by different agencies or independent parts of the same organisation.

Separating housing and care can be seen as one aspect of the economic notion of the division of labour which states that each organisation can be more efficient in providing a distinct service within the service 'chain' than one organisation providing a wide range of services. In 'developed' countries, there is a trend towards an increasingly specialised service system, where each element of service is provided by dedicated providers. Whether this results in better care, let alone improved outcomes, is though yet to be definitively proven.

## **Aids and adaptations**

There is an urgent need to provide housing that meets people's needs as they grow more dependent. This implies not only that housing should be accessible to the elderly, but also that it should be adapted to their needs. The 'aging in place' model implies that apartments and dwellings should be able to accommodate an elderly person right up to the stage where they become wheelchair and ultimately bed and stretcher-bound.

The Committee for Experiments in Housing (SEV) in the Netherlands has shown that care needs in well-adapted housing are less than in the old arrangements for independent living. This is largely due to three factors: the better layout of the home; more efficient clustering of clients and the effect of a 'protective community environment'. Swedish research, which has compared new residential care with 'normal' settings has found a reduced need for care in more homely settings. The common sense explanation for this might be that the more an individual's needs are met in their home and social contacts, the less they tend to seek formal care.

## **Housing models**

Cutting-edge international practice suggests that home care, even for the very disabled elderly, can be provided cost-effectively at home. The key to this seems to be very well thought-through care coordination arrangements and a well-developed community support infrastructure. In reality, without this support or structure, most home-based care is unlikely to be cheaper than care in rooms or apartments in a residential complex, due mainly to economies of scale and transport/travel costs.

Home care in apartments or dispersed private homes can meet the needs of many - if not most - older people and there remains a place for nursing homes and other intensive-care settings for those whose medical condition is unstable. Nevertheless, the needs of the elderly as a group cannot be completely met either by provision of care in their own home or, if this is not possible, by intensive residential care. The challenge is therefore to create residential models that combine the advantages of a private apartment with the economies of scale required to fall below the cost of nursing home care.

In the UK, policymakers have tended to be concerned primarily with expanding and refining the role of the social services department, with the result that some successful service models, eg shelter-with-care have tended to be neglected. One prominent academic has commented (to me in correspondence) that "the British problem is that the separation of housing from community care at all levels of

government has made everyone very slow to recognise the variety of potential circumstances and the wishes and models to fit them."

Public and private interests are converging in a search for 'affordable' residential care in a form that is more livable and "user-friendly" than that of the nursing home. Increasing attention is now being focused in other countries on intermediate types of housing provision, ie various forms and levels of sheltered housing and assisted living (AL) arrangements.

Such AL settings have the advantage of blurring overly rigid definitions of services/care and housing, while leaving it open to both elements being separated out. This leads to more effective (and better value for money) care, since typically housing is no more expensive than in other residential settings while care is lighter, which means in turn that care can be improved. The American evidence on AL living is that it can be a flexible model of service and serve low income and other older people, with different levels of disability, more cost effectively than nursing home care. In Oregon, for example, the public costs of AL are pegged at 80% of nursing home rates.

But the AL model is not free of dangers and difficulties. These include the administration of medication, nursing practices and fire safety codes. In the USA, the main tension arises between the desire to ensure safety and regulate standards to come close to nursing home levels and the philosophy of giving the individual maximum autonomy (which can conflict with safety) and minimising unnecessary regulation.

As one report on AL put it: "it is impossible to improve environmental standards, serve a nursing home-level clientele, insist on regulations comparable to nursing homes and save money."<sup>1</sup> But with some regulatory relief and flexible staffing patterns, there is emerging evidence (from Oregon) that money can be saved. Since public authorities cannot ignore the safety of residents who receive state subsidised care, methods other than regulation are needed to provide protection. Alternative strategies include: stringent front-end licensing, case management, negotiated risk, consumer education and legal redress for clients and their families.

While it is hoped that assisted living will move away from a medical model of care, some fear (with some validity) that this shift may lead to worsened health conditions and increased morbidity and mortality of residents as a result of less supervision, fewer qualified staff and worse access to medical care. Others worry that the philosophy of assisted living will be compromised in the battle for profits and occupancy and AL may end up providing a stripped-down, less well-staffed version of nursing home care without the extra amenities. There is also a worry that growth in residential care (of whatever sort) will undermine the growth of home care programmes.

Good practice in housing and care has come through two main 'process' channels at

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<sup>1</sup> *Assisted living in the United States: A new paradigm for residential care for frail older persons?* AARP Paper, Rosalie A Kane and Keren Brown Wilson, 1993

the central and local levels respectively: ensuring central government departments consult each other and work together and overcoming problems faced by providers at a local level. For example in the UK, health care is free while housing can be very expensive - creating incentive problems. In the Netherlands, the organisation 'SEV' brought different innovative local housing projects together and identified the regulatory and financial problems. SEV also worked with health and housing ministries to solve bureaucratic problems and produce acceptable outcomes for all parties concerned.

#### **4.3.5 Regulation and quality issues**

##### **Models of regulation**

In the UK, there is a tradition of light-touch regulation or 'self-regulation', which has hitherto encompassed many aspects of life and the way the individual interacts with the State. This British tradition and approach, replicated and elaborated to a greater or lesser extent in New Zealand and Australia, is coming under challenge from the American model of litigation, contract law and a top-down regulatory approach, with standards laid down and (sometimes patchily) enforced by Federal or State agencies. Examples of this US type approach are the regulation of nursing and residential homes, the operation of the Food & Drug Administration and detailed regulations enforced on pilot projects in the long-term care field, such as the Cash & Counselling Demonstration projects.

##### **A changing quality focus - from self-regulation to quality 'standards'**

Simply because there is not a 'top-down' or legally codified list of quality standards does not, of course, mean that institutions have not in the past monitored and enforced quality. It is a myth that a concern with quality is a late 20<sup>th</sup> century invention. For example, the matron of a British hospital performed a clear 'quality-monitoring' role. She, together with senior doctors, traditionally ensured that care was provided smoothly and punctually, that wards were clean and tidy and individual patient details and requirements were not overlooked.

Other examples of historical hospital quality activities were hospital rounds, death committees and autopsies, shift handover procedures, journal clubs and scientific meetings. Many of these 'quality' activities were not quantified, measured or evaluated, as is the current expectation, but nevertheless were an important part of the health services culture.

All over the world, the focus is now increasingly on accreditation, 'total quality management' and risk-minimisation programmes - reflecting a more modern obsession with market-driven and legalistic approaches. Hence, there is a discernable international shift away from a focus on standards of physical facilities, adherence to recorded standards and a task-oriented emphasis on process and towards a focus on training, improved information/documentation and measurement of both processes and outcomes. Examples of these trends are:



training: an expanded undergraduate and postgraduate curriculum for medical students to include communication skills and an understanding of the role of other professionals and a philosophy of continuing education;

improved information and documentation: with health care and social services now being provided from an increasing number of locations, more use is being made of IT and single client records so that tests, interventions and service provision can be recorded, shared and monitored;

a focus on both processes and outcomes: these include evidence-based guidelines, accreditation, multidisciplinary quality measurement, care protocols, clinical audits, practice reviews and indices of effectiveness rather than simple efficiency.

This approach is in some ways more rigorous than the older method of self-regulation and has many positive implications for quality. But there is also a potential problem of market failure whereby field agencies alone cannot develop integrated second generation assessment methodologies, protocols, databases and packages for management and administration without government (Health Department) help.

However, more formal methods of improving quality need not be - and are probably best not - done by devising central rules and regulation, followed by inspection and sanctions for failure to meet standards. Rather, good organisations see quality as something that is best done bottom-up, which everyone strives to do, all the time, in local settings. Feelings of ownership, involvement and pride in doing a good job are hallmarks of such institutions. The problem is that approach works well with committed people and organisations, but works less well where keeping costs down is a key driver and the products and services delivered are routine. No one solution works in all environments.

In the UK and other developed countries the location for acute care interventions and treatment of chronic long-term illnesses is shifting (rightly) to settings other than hospitals. While care at home and in more homely settings may be what people want, this exposes the need for quality assurance (QA) criteria to be developed and applied in these different, and often less formal, locations. This has resulted in UK initiatives to improve the quality of care in residential settings. It is clearly impractical and uneconomical to transfer QA programmes designed for institutional environments to other locations, eg day and community centres and people's own homes. This will become an increasingly important issue: the assessment of the coordinated care pilots is expected to shed light for example on how to improve quality through continuity of care.

### **Links between quality and outcomes**

There is a virtuous link between improving quality and focusing on outcomes. Any impetus given to the measurement of health outcomes by policy direction, government research and funding is likely to lead to improvements in the measurement of quality and, in turn, to health outcomes. Internationally, there are many positive signs that aspects of quality measurement are being incorporated into health systems and these are leading to better health outcomes.

An example of international action in this area (quoted by Helen Lapsley in Bloom A, 1999) is the fact that the Australian Health Ministers Advisory Council has commissioned a National Expert Group on Safety and Quality in Health Care to produce a national action plan on recommendations to improve health care safety and quality activities. The Commonwealth Department of Health is vigorously supporting a health outcomes focus and has financed and supported helpful activities such as the coordinated care trials, reduction in adverse drug reactions and the application of best practice.

Nevertheless, evidence of health outcomes, while important and arguably essential, cannot be the only dimension by which quality of care is evaluated as not all patient outcomes are directly related to the quality of care provided. Outcomes are complex, dependent on actions outside the health system and are often subjective. For example, outcomes may include not only the five Ds - death, disease, disability, discomfort and dissatisfaction - but also return to home or work, re-admissions, quality of life/stress and general health status.

### **Links between quality and cost**

Reasonably encouragingly, there seems to be little overall link between quality of care and cost. Although no clear evidence yet exists, early indications from international trials seem to indicate that high quality, coordinated, care is not more expensive (and is certainly higher quality) than traditional care services. But, let us look at each cost driver in turn:

first, countries which have looked at the **costs associated with population aging** have concluded that the costs are likely to be manageable over the medium term (30 to 50 years). For example, UK experts concluded that on a reasonable central projection of trends, costs were likely to rise by about 2.5% a year over the next thirty years, raising the share of GDP taken by long-term care by only around 0.2-0.3%;

second, the rising **cost of professional, and especially medical, care** means that the real costs of acute (hospital) care will probably rise in the short-term, although it is unclear why these costs should rise faster than the real increase in medical wage costs multiplied by the labour share in total costs with some allowance for increased specialisation. However, the rate of hospital admissions of the elderly is also rising in many countries. But earlier intervention, prevention measures and better primary care may well be able to stem or reverse this trend, as demonstrated in the Netherlands;

third, increases in the **volume and quality of care** due to the recognition of past under-servicing - are potentially a significant cost driver. But, even here an increase in costs is not a foregone conclusion. It is important to separate out effects from the increase in the volume of care from changes in quality. The pure quantity effect - increases in the amount of care (eg hours and/or intensity) already provided - clearly increases costs, although even this effect will be offset to the extent that the use of other services are reduced (eg prevention of later hospital admission). It is possible to raise quality by

improving the efficiency and effectiveness of services without raising costs. In many ways, the key question is whether the drive to home care can raise quality without increasing overall costs. Evidence from the Australasian coordinated care trials will not be available until spring next year at the earliest.

It has yet to be seen whether the global drive towards home-based care, the coordination of chronic care for the most disabled and maximising the contribution of family and voluntary carers will raise costs or not. There is certainly no strong evidence that domiciliary care is necessarily cheaper than residential/nursing home care for the elderly with more complex chronic care needs. The issue is whether the balance of provision needs to be tilted away from institutional provision and towards home-based care at the margin. Most countries believe this needs to be done, but the cost-effectiveness of doing so has not yet been fully investigated.

### **The future of quality assurance**

Some discernable quality trends are as follows:

- i) the appropriate use of technology will become increasingly important in the assessment, treatment and measurement/monitoring of care;
- ii) technology is changing rapidly, and training and staff usage patterns will need to reflect these changes rapidly and flexibly;
- iii) formal QA assessment and measurement will inevitably become more visible and incorporated into clinical and managerial accountability processes;
- iv) there will be growing pressure to demonstrate (eg to Parliamentary Committees) the effectiveness of QA processes;
- v) the public will become increasingly litigious;
- vi) evidence-based medicine (EBM) guidelines will become routine. Best practice is already focusing on developing better quality clinical outcome measures and striving towards effective and appropriate resource use;
- vii) health outcomes will be used as a quality measure, but with a recognition that health interventions are only one factor in producing good outcomes.

### **The role of Information Technology**

Information Technology (IT) will also play a more important role (will patients in the future routinely consult the Worldwide Web for information about the effectiveness of procedures?). In some places GP surgeries, pharmacies and hospitals are already developing IT links with each other. But in most countries, and certainly in the UK, more comprehensive clinical information systems are needed.

IT systems need to be accessible, with due safeguards, to social care agencies. Much of the data required for effective and coordinated treatment already exists and

is collected somewhere, but it is neither integrated nor readily accessible by all the relevant players. Issues which will need to be addressed in implementing a coordinated data strategy include data security, legal implications, patient access to health records and the roles and responsibilities of the care professionals involved.

Dedicated electronic databases and a good deal of management commitment will be required to tackle this situation. The collection, analysis and dissemination of quality data has a cost, but there are certainly large *opportunity costs* of inappropriate, unnecessary or inadequate care and treatment which are likely to arise from the absence of such data. Avoidable care complications such as adverse drug reactions and post-operative wound infections - requiring longer hospital stays and additional therapies - will be more easily identified by better data systems. The use of routinely generated data through standardised approaches like assessment, eg the US MDS methodology can produce useful quality indicators.

#### **4.3.6 Staffing issues**

Community care is labour intensive and staff are the key resource: around 70 to 80% of long-term care costs are labour costs. Due to financial pressure, institutional facilities have cut staff numbers and hours in recent years, resulting in highly pressurised and potentially low quality care in spite of the needs of highly dependent people, eg 1 worker trying to feed 12 to 15 people at mealtimes.

There are several interrelated staffing issues including:

- low wages;
- the long and unsocial hours;
- the menial and physical nature of the work, eg lifting, etc;
- the perceived low status associated with care work;
- poor training opportunities and the lack of a career structure.

As a result of these difficulties, the recruitment and retention of staff is becoming harder in most advanced industrialised countries as young people now have more opportunities and as increasing affluence breeds a desire for 'clean', non-menial or creative work. For governments, especially as they try to work in a more 'joined up' way, there are likely to be long-term effects, such as on pension levels and future social security costs, from the poor conditions of service in the care sector.

The old advantage of care homes being able to offer 'flexible' hours to suit people with family commitments has diminished now that other employers, eg supermarkets, have moved to offer flexible contracts to attract part-time staff. A big problem is the inability of UK social services departments to offer certainty of a given amount of hours, which together with the lack of training and hence the ability to command high wages, makes it impossible for people to risk coming off benefits.

This is a problem that will worsen with the affluence of the society unless attitudes change. The country with the highest GDP per capita visited - Sweden - is beginning to face real shortages of nursing and care staff and other less affluent countries will feel this problem more acutely as time passes. Partly the problem is attitudinal - the widespread perception that working with older people is unrewarding and menial.

With a third of the population to be composed of people over 65 in the next 20 to 30 years, this is not an attitude that is either humane or sustainable.

But, equally, Department of Health publicity campaigns about the benefits of working with the aged are not, on their own, going to change attitudes much. The status of being an 'Elder' needs to be enhanced in practical ways, including allowing people to stay on at work longer, boosting opportunities for older people to do voluntary work and encouraging inter-generational programmes where there is interaction with children. Practical changes to the career 'deal' and training opportunities and requirements will also be required as the nature of the work and the wages are unlikely to change in the short-term.

The evidence is that the reputation and consistency of presence of LTC providers is an important factor in being able to recruit workers and volunteers. The ability of organisations, which can draw on religious, trade or political connections, also helps in recruitment.

### Need for a career structure for LTC workers

Individuals' and advocates' concerns about the quality of care - due to poor skills and inexperienced staff - are one of the symptoms of the lack of a clear and attractive career structure. Given the lack of clear reward associated with greater experience for care workers - which contrasts markedly with the system for doctors - the fact that there is high turnover and low skill levels is not surprising. There are often 'glass ceilings' at certain points in the career structure, which prevent hospital auxiliaries becoming nurses or care workers becoming care managers. Conversely, nurses who are struck off the register are able to take up a post as a care assistant, which seems unsatisfactory.

A career structure is something that has been thought about in the UK in connection with nursing, but not so much in the context of non-medical personal care. However, the difference in career structure and qualifications between nurses and care assistants do not reflect levels of responsibility in any systematic way and look unsustainable in the long term. Training for nurses and care workers needs to be more meshed and some training providers (eg University of the South Bank) already have a combined Department of Health and Social care. In Sweden they have made recent progress in inserting medical training into the standard social workers training course.

### Multi-tasking - a good or a bad idea?

Multi-tasking is likely to become more necessary due to several factors: downward pressure on budgets, resulting in higher case loads; lower staffing ratios, resulting in the need for more flexible rosters and care patterns and the greater dependency of older people in community care programmes. One model is that teams could have different types of workers working together, including:

**'boundary workers':** community nurses/district nurses and social workers;

**'central workers':** nurses and GPs;

**'specialists':** psychiatric social workers, community psychiatric nurses, psychiatrists and geriatricians.

At the moment, community nurses tend to be restricted to performing medical procedures, eg intravenous injections when they have the capacity and interest in doing more personal care and preventive work, eg on hydration and nutrition. Many people feel there is a good case to be made for a generic level of care professional, as mentioned in the Griffiths Report, which would encompass people from widely different disciplines, eg nurses, social workers, physiotherapists and OTs. Creating such a worker would allow a more holistic way of working.

An NVQ in care is seen as providing the 'entry gate' for access into either nursing or social work. But there needs to be a viable career for nurses and care workers who do not want to enter management. The route for this is probably by enabling people to: take more responsibility, have opportunities to work more flexibly and to specialise in particular areas of care, eg psycho-geriatric care, rehabilitation, etc.

## **Training**

The UK experience with under-skilled care workers is borne out in other countries. The PSSRU Darlington Study (D Challis et al, *Care Management and Health Care of Older People*, 1995) showed that it is possible to train untrained staff to do a variety of jobs. There is a clear need for more training on the care of older people at all levels, from hospital specialists and managers at one end to the care workers themselves at the other. There is also the need to make better use of the training that some groups receive. For example, some nurses pick up allied skills, such as physiotherapy, in the course of their training, but are not encouraged to, or do not, use these skills in the working environment. This represents a lost potential for synergy and better treatment. Enhanced training for care assistants is a high priority, as these workers spend a large amount of time in contact with older people.

There is a problematic boundary between education services and the training needs of the health service - or the demand and supply aspects of training - which needs to be addressed. The supply of training up to the level of nursing and medical qualifications is provided by education services (schools and colleges), while training demands are created by the health service. One answer to this issue being looked at in New Zealand and elsewhere is to devolve total training budgets and associated services to care providers.

The supply of trained workers is only likely to be forthcoming if the rewards of the training - in the form of wages - are sufficiently attractive. Care workers are among the lowest paid service sector staff at the moment. It is pretty clear that entry level wages and progression through the hierarchy need to be addressed.

The demand side is less problematic - employers are crying out for enthusiastic and well-trained staff. The key sticking point here is the ability of employers, given the incentives on public sector purchasers to bear down on costs, to pay higher wages to attract the type of staff they want.

Most people believe that training needs to be continuous and based on a clear premise of improving quality. Managers and care workers have different needs. In residential homes, managers are de facto case managers and therefore ought to receive training on observation skills and general gerontological training to develop awareness of problems facing older people. Case workers may, however, need training in how to manage a case load, budgeting issues and practical skills around lifting, usage of technology, etc.

In Australia, best practice organisations recruit people with two years experience of working on a TAFE course looking after older people and a first aid certificate. They offer people internal training looking at the values, code of conduct, boundary setting, infection control and personal care training, and provide regular health and safety assessments.

Given the high percentage of elderly people in the formal health and social care system, the medical profession - hospital doctors, nurses and GPs - needs to have systematic, basic training on elderly care issues. Those wishing to specialise in elderly care or general practice, where they are likely to meet a lot of elderly people, must undergo thorough specific training. Once trained, geriatricians and equivalently trained social care and nursing staff, must be recognised as being the source of expertise on the care of older people and appropriately rewarded.

#### **4.3.7 General observations**

##### **Inappropriate stays in hospital**

***"It appears that for older patients, rates of inappropriate use of acute care beds are about 20% for days of stay... The principal reason for inappropriate use of acute hospital beds is lack of availability of care at an appropriate level, primarily long-term care. These patients appear to require care that is in between the level of [a]... patient hotel and the acute hospital."*** {*Acute Hospital Care: Final Report*, March 1999, UK Centre for Health Economics, commissioned by UK Department of Health).

According to a review of the international evidence on the inappropriate use of acute beds and the cost-effectiveness of care in different locations commissioned by the UK Department of Health (see quote above), there is still evidence of the elderly<sup>2</sup> spending too much time in hospital, both in the UK and in other countries, although the incidence of this appears to be declining.

Rates of inappropriate use of acute hospital beds seem to be higher for geriatric patients than for the general population, and inappropriate *admissions* are also a problem, though less so. Discussions in the course of the Fellowship with

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<sup>2</sup> In this Chapter, and elsewhere in this report, where the term 'geriatric patient', 'elderly' or 'older person' is used, it refers to someone over 65. The reason for this choice is that 65 is the most commonly used, and internationally understood, reference point compared to other years such as 60 or 70.

international experts and practitioners suggest that older people can be safely and well cared for in their own home - rather than in acute or sub-acute care - to a greater extent than is still commonly done in the UK.

Both nursing home care and home-based community care can substitute in part for hospital care, although there will still be a requirement for acute hospital care. US practice has shown that substantial downward cost substitutions are possible by treating people, eg for infections, who are already in nursing homes *in situ* rather than in acute beds. The USA is also experimenting with hospital-at-home type schemes, where more technically sophisticated procedures are carried out in the home environment supported (and occasionally carried out) by informal carers. The relevance of this to the UK is tempered by the fact that US nursing homes have a rather different skill mix (more nurses and specialist clinicians on site).

In terms of costs, research seems to find that *long-term* costs are lower where hospital use is minimised, although *short-run* hospital costs may increase. There is evidence that appropriately targeted and resourced case management programmes can keep people successfully at home. The report quoted above on the international evidence states that "most studies have found that the costs of long-term care in locations other than hospitals to be either similar to, or cheaper than, hospital care".

### **Positive results from case management and discharge planning**

***"The evidence on the effectiveness of various forms of discharge arrangements in terms of reducing delays in discharge has led to a plethora of official reports in the UK on best practice... and guidance for purchasers and providers... Despite this, there appears to be persistent shortcomings... with detrimental effects both for patients and for the efficient use of hospital resources."*** (Acute Hospital Care: Final Report)

Another finding is that not only the elderly still tend to spend an unnecessary amount of time in hospital but also that case management programmes can succeed in helping to ensure that appropriate care is delivered. The previously cited Acute Beds Study stated that "discharge planning, comprehensive geriatric assessment and carefully targeted case management appear to have potential to reduce the use of hospital beds." They came to the conclusion that "certainly, community case management programmes maintain more people in their own homes for longer than 'standard' care."

It is not the case, though, that case management will *necessarily* or *automatically* produce greater efficiency or equity. The evidence shows that such programmes need to be carefully targeted at the results they are seeking. For example, if the aim is to reduce the numbers of people admitted unnecessarily into residential or hospital care it is necessary to target resources at those most at risk of entry to residential care, not those with high needs, eg the frailest elderly.

Authorities which have led the field in establishing case management programmes, eg Kent Community Care Programme (CCP) in the UK from around 1976-1988 and the Community Options Programme (COP) in Madison, Wisconsin, allowed the elderly to stay at home rather than entering institutional long-term care. Some



experiments with providing case managed community care show it appeared to postpone entry to institutional care for about 2 years. Others, eg the 4 year follow-up of the Kent CCP, showed that, for many, appropriate care management prevents admissions to institutions altogether, except for care in the terminal stage of illness (cf *British Journal of Social Work*, Special Issue, 1988). The Wisconsin COP is an excellent example of an innovative intensive home care scheme (see the Best Practice Section in the US chapter).

## **Comprehensive geriatric assessment systems**

**"In the UK, a recent review of systematic evidence relating to rehabilitation concluded that one of the few areas in which there was evidence to illustrate the effectiveness of these interventions was indeed comprehensive geriatric assessment."** (Acute Hospital Care: Final report, op cit)

For clients with complex care needs, what is crucial is that someone - not necessarily a medically trained person - has an overview of the services provided to the client. That person can ensure that the relevance and quality of care is maintained, eg by undertaking or ensuring that a full care assessment is made and then monitoring and adjusting the care plan regularly. Medical personnel (eg GPs) are often too busy to undertake this function effectively.

Provision of comprehensive health care to patients requires a wide range of health care and other professionals applying very specific skills. The creation of 'horizontal' or 'virtual' systems therefore has far-reaching implications for virtually every aspect of the care process, eg staffing requirements and training, care procedures, protocols and information systems. While the individual client may be more involved in, and probably more responsible for, their care, there are important safety issues which still need to be addressed, eg under which circumstances a client can professionally and ethically be left unsupervised (the issue of regulation is discussed further in a separate sub-section below).

Research suggests, however, that multidisciplinary teams tend to work in mono-disciplinary ways unless some quite demanding conditions are met, which are discussed further in the Funding section below.

Meta-analysis of a number of controlled studies from the UK and elsewhere (cf Acute Hospital Care: Final Report) reveals that the type of comprehensive geriatric assessment (CGA) system used matters in terms of outcomes delivered. Specialist in-patient assessment units and home assessment services, for those without a recent discharge, produced a significant reduction in mortality, while other forms of CGA did not. The report showed that programmes which had control over the medical recommendations and provided extended follow-up were more effective. The main impact of CGA is to reduce the number of patients who are referred unnecessarily into residential and nursing home care. Some of the Australian Coordinated Care trials and the ElderCare Canterbury Project in New Zealand are examples of successful CGA systems.

It is not simply a question, however, of treating single diseases and medical events more efficiently and effectively. As the number of deaths from, for example, coronary

heart disease are reduced as a result of effective medical care and prevention programmes, more people will reach advanced ages and risk contracting cancer, dementia and other examples of substitute and co-morbidity, with the consequent high costs of care. The emerging challenge - which has not yet been adequately factored into health policy and planning - is to calculate the lifetime health outcome and cost gains from treatment or prevention of diseases *taking account of other health risks*. The existence of co-morbidity means that the benefit per unit cost of treatment is likely to be lower than claimed on a single disease basis.

### **Appropriate definition of the 'catchment' area?**

It is a moot point as to how large a geographic or population area can effectively be served by an aged care service aiming to deliver seamless care. In Britain, Social Service Departments (SSDs) or Primary Care Trusts (PCTs) will increasingly be aiming to work together to deliver integrated services. These bodies will have a catchment area of between 100,000 and a quarter of a million people. International evidence shows that a catchment area of about 250,000 to 400,000 people and around 35,000 to 50,000 people aged over 65 is a good size to operate a comprehensive public elderly care service.

It is worth noting (and thanks to David Challis at PSSRU for this point) that most London boroughs, Welsh and Scottish LAs, many metropolitan districts and all new unitary authorities are too small to meet this 250,000 to 400,000 efficient size criterion. Small HAs in the UK may be squeezed between the fact that they aren't providers unlike PCTs/PCGs and the fact that they are too small to be sensible commissioners. The trend towards smaller LAs makes them only viable as provider units, as in Wisconsin, USA, and a local unit of planning and commissioning is needed, as in the USA and Australia with state governments.

In New Zealand, the ECC coordinated care pilot has a catchment population of around 300,000 to 400,000 and aims to serve about 50,000 elderly over 65. The Australian coordinated care pilots are quite a bit smaller - perhaps covering 50,000 to 100,000 people, but they would probably be expanded to cover larger areas if they were continued. Most US experiments in fully integrated care, eg the PACE programme, are specifically designed to cover only the most frail elderly and are not part of a county or state wide programme. These programmes cover several hundred elderly, for whom total care and case management is provided.

A growing number of states provide some more integrated care programmes in the guise of Community Options Programmes (COPs). Wisconsin, for example, runs a state-wide programme and, perhaps in the future, Minnesota will do so through ensuring that people have access to comprehensive services through a number of licensed care insurance providers.

### **Delivering services in rural areas**

In all countries, delivering care, eg primary care services and 24 hour personal care-type services - in rural areas is a challenge. The larger the distances, the greater the complexity of the task. The problem is faced most acutely in Australia and New Zealand, but is also evident in parts of Europe, eg rural Germany. The way these

countries have tackled the problem has lessons for the UK.

Of the countries visited, Australia is perhaps most advanced in addressing the problems raised by rural service delivery. Two main strategies have been adopted:

new service delivery models. For example, new rural service units called 'multi-purpose services' (MPS) have been set up to provide a 'total' health service/one-stop shop. These units bundle together primary, community and residential services for the population of a particular area. Helicopter paramedic and 'flying doctor' services are also available for emergencies;

technological solutions. Video conference, teleworking and remote access technologies are being developed to enable professionals to give advice and perform services for rural clients from a different (usually urban) location.

The MPS model appears to be working quite well and has the advantage of utilising scarce capital and equipment very efficiently. The premises visited in a remote part of Victoria, Australia, did everything from acute, but straightforward, surgical interventions to childminding for a catchment area of around 35,000 people. The area of greatest pressure in long-term care was on residential care places. These services cannot sensibly be based in outlying areas since they need to be of a certain size and have good access to acute facilities given the nature of their clientele.

The size of the catchment area for these services is an important issue. How far can these services be provided on a sub-regional as opposed to a local basis? The Australian Government is thinking of expanding the size of the area covered by MPSs. The availability of technology and economies of scale will probably determine how large an area such services can cover.

Some rural areas are seen as a desirable place to live and can attract health professionals who chose to retire and/or do part-time work in the area. But in the absence of such local skills, policymakers may need to think about appropriate incentives to encourage primary care physicians and other professionals to live and work in some rural areas. Inevitably, very remote areas will by their nature be cut off from mainstream services, and access to reasonable transport and phones is crucial.

### **Preventive health strategies**

Preventive health strategies, 'healthy aging' and 'active aging' policies fit well with the idea and premises of home or community-based care. 'Healthy Aging' strategies are aimed at preventing illness and disability and promoting wellbeing and participation. Many countries across the world are now taking initiatives in this area. Examples include the Australian 'National Healthy Aging Strategy', the New Zealand Ministerial Taskforce on Positive Aging and the UK 'Better Government for Older People' initiative and 'Prevention' grants to local authorities.

While this focus on 'wellness' is positive, the evidence on the effectiveness of such interventions is, by the standards of evidence-based practice, relatively limited. Academics such as Stuck have argued that the effectiveness of care depends on the

pro-active nature of intervention. As mentioned elsewhere, interventions which delay the onset of disease may result in 'substitute morbidity' (eg cancer replacing CHD as the single or main cause of morbidity) or increase co-morbidity (where several chronic conditions co-exist, eg dementia, hypertension or organ failure).

A widespread problem is that despite the rhetoric, few resources are really directed towards prevention. A key question that needs to be addressed in designing or putting in place programmes is 'prevention of what?' Unless policymakers are clear precisely what behaviours or illnesses they are trying to target, then prevention is unlikely to be successful. 'Wellness' strategies need to be carefully thought through and, ideally, costed in terms of lifetime cost and outcome impacts, as well as being elaborated in specific directions and towards particular goals.

In the UK, there are two sorts of prevention programme - first, the prevention of institutionalisation and, second, a broader preventive agenda. The *first type of programme* involves initiatives such as relieving carers so that admittance into a nursing home on a permanent basis is not necessary, or 'flying squads' who work with local GPs in preventing the institutionalisation of frail elderly clients in moments of crisis - for example, if there has been a fall or non-serious crisis in the night. The Australian Care 21 coordinated care pilot has trialled a service of this sort called 'GP-link' with very similar objectives.

The *second type of programme* - for example, that run under the Better Government for Older People programme in the UK aims to enhance the environment for older people (transport, adaptability of homes, pavements, etc) and promote health and activity, so that older people can play a fuller part in society. International best practice suggests that such broader preventive health strategies need to start in a primary care setting or at least in between primary and acute care settings. Components of such a strategy will include education, assistance and prevention programmes based on a philosophy of looking at what it takes to be well. Examples from the US (see Centre for Healthy Aging example in the Best Practice Section of USA chapter) of useful interventions include:

a 'Partners in Health' scheme, where a nurse will go to a home and do a case assessment. S/he will then make recommendations for ways to improve that client's health status and provide follow-up monitoring of services delivered;

a psychiatric day rehabilitation programme;

using volunteers to provide services, which mainstream programmes are not providing, or cannot provide. Such volunteers, however, must have a serious structured training programme and proper supervision through a counsellor.

#### **4.3.8 Health and social care policy in the United Kingdom**

A good deal of policy innovation has taken place in the UK at the end of the 1990s. The latest set of UK policy initiatives taken by the new Labour Government to remove barriers to joint working mark a positive step towards better collaboration within and between health and social care services and begin to put patients at the heart of the care delivery process. The agenda of improving coordination of services

has been squarely tackled, and the effort involved has been admirable.

But it may be a case of too much, too quickly. A concern voiced by NHS managers and people trying to improve care in communities on the ground is that the Government is at risk of trying to do too much with a plethora of separate initiatives. These include, to name but a few: new Primary Care Groups /Trusts, Health Improvement Programmes, National Service Frameworks (eg for Older People), Health Action Zones, National Priorities Guidance (for social services), Better Government for Older People programmes. There is a risk of not delivering the desired outcomes in each as a result all this activity. There is a serious danger of 'initiative overload' at the local level: in Merseyside, for example, there are a total of 61 initiatives running concurrently in summer 1999, of which 23 are health or social care initiatives.

### **The 1999 Health Act**

The 1999 Health Act granted significant new operational flexibilities to health and social services. It used to be possible for the NHS to transfer monies to local government under powers granted by the 1977 NHS Act (where better value would be achieved than by equivalent NHS expenditure), but local authorities were never able to transfer money to the NHS. The 1999 Act's legislative powers to pool health and social services budgets, enable lead commissioning and allow integrated provision, among other changes, removes important legal barriers to joint working.

These legislative changes *could* have a massive impact, but much depends on the speed of take up and willingness to co-operate at a local level. Experience shows, however, that 25 years of joint working have not solved boundary problems or even, in many cases, facilitated significant cross-boundary working. There is no reason to believe that the latest initiatives, without firm action, monitoring and dissemination will be any different. Large bureaucracies are notoriously conservative in their actions and, in the past, neither the NHS or local authorities were renowned for the dissemination and speedy take up of good practice.

### **The Royal Commission's Report and remaining issues**

The Report of the Royal Commission on Long-term Care covered a lot of ground and published a wide-ranging report in March 1999 (see Annex for summary of main recommendations). One weakness of the report - reflected in its divided opinion - is that it did not clearly explore and articulate the reasons behind its decision to recommend that more national resources should be put into long-term care to ease the financial burden on current and future beneficiaries of the long-term care system. They recommended easing the means-tests and making personal care free at the point of use - as opposed to putting more resources into improving the quality of care.

Therefore, despite the UK's recent policy initiatives and the energy going into these initiatives at a local level, reflection and comparison with other countries shows that problems are likely to remain. For example, the UK Government remains simultaneously committed to the principles that:

health services should be available free at the point of use, on the basis of need;

local authority social services should be charged for.

This dichotomy underlines the major distinctive area of weakness in the UK - namely the different financial and charging regime for health and social services. Introducing more charging or means-testing into the NHS would renege on a key, and politically very popular, principle of the NHS. However, expanding the services provided free at the point of use by the health service would be potentially pretty costly and do little to improve quality - a key commitment of ministers. Stated in this way, it is doubtful that direct action to resolve the charging boundary is feasible - at least in the short run.

But, equally, without some action to genuinely bring together staff and finance to deliver coordinated care, there must be doubt that the UK problems around joint working will really be solved. Since introducing widespread charging for health services is unlikely to be politically feasible in the UK for the foreseeable future, it is hard to see how equity issues - for example, regarding charging - can be resolved in the longer term without a fundamental change in how long-term care is managed and funded. Some have argued (eg B Davies, *Thinking Long in Community Care*) that the more government presses for coordination (through enforcing pooled budgets and exhorting behavioural change) without a fundamental change in charging arrangements, the more powerful are the distorting incentives created by the opposing principles governing health and social services finance.

The current policy direction of exhorting and enabling local and health authorities to enter into partnerships moves in the right direction but, at one level, does not grasp the nettle and resolve the fundamental cultural, charging and administrative boundary issues between health, social services, housing, employment, leisure services, etc. Examples of outstanding problems, mainly reflecting the division of responsibilities between the NHS and social services, where the current policy orientation or instruments seem inadequate include:

historically, there have been few uniform and clear objectives for long-term care and a lack of clarity about aims and objectives. However, this ought to be somewhat remedied through the new 'Modernising Government' focus, ie the policy orientation in the Social Services White Paper and a new performance management framework;

an unclear legal framework for PSS (eg Gloucester and East & North Devon Health Authority cases, among others). This has meant that the provision and withdrawal of services is subject to intermittent legal challenges;

the absence of a single decision-making process for access to care (eg no mandatory national means test for domiciliary care) and the fact that eligibility criteria for NHS Continuing Care vary significantly between health authorities;

funding pressures on social services departments have meant that quality has had to be compromised in some instances and funds spread over too many (or, conversely, through an over-targeted approach, too few) clients;

horizontal inequity. Individuals placed in NHS-funded nursing homes bear no costs, while local authority clients are assessed for the full cost of care. Another example is that domiciliary care is chargeable if provided by a care assistant but not if provided by a community nurse. The Royal Commission's main recommendation was addressed at this problem;

little consistent and comprehensive information across health and social services on costs and activity in PSS. The NHS has also historically been poor at spreading best practice;

poor targeting of interventions, so that inputs are not systematically placed where their marginal productivities are highest.

In the latter case, while UK policy has grasped the notion that it is important to tailor resources used according to case complexity, academic research by the Personal Social Services Research Unit (PSSRU) and others shows that it is simplistic to reduce the complexities of care management arrangements, budget span and delegation and the resourcing of teams to a uni-dimensional concept of case complexity. The way that labour, capital and other inputs are combined in order to increase 'marginal productivities' is a key determinant in improving outcomes and service effectiveness. Most authorities have not yet thought carefully about how all their resources can be combined most cost-effectively.

Other problems which are shared with other countries are the difficulty in getting different professional groups to work together and the fact that best practice in the UK is often poorly disseminated and patchily implemented. There are some specific areas, for example links between the hospital and the community and more flexible housing options, where the UK can learn from other countries.





## Possible solutions

There is also no easy solution to current organisational boundary problems. Major changes to the organisational framework would be extremely disruptive and unpopular and would create new boundary problems. If wholesale organisational change is ruled out, there are three directions in which current organisational problems could be addressed:

**NHS-led coordinated care.** For example, the newly created Primary Care Groups could be given the lead in organising coordinated care;

**local government coordination.** Here, local government's role in organising and managing long-term care would be enhanced, eg perhaps through giving control and responsibility over community nursing and rehabilitation to social services authorities;

a **new agency charged with coordination**, an agency (or separate agencies for client groups, eg mental health, older people, perhaps children) is given the responsibility to plan and deliver coordinated long-term care services.

Whichever option was chosen would need to build on, not reverse, the practices and lessons emerging as a result of existing coordination arrangements, ie pooled budgets. There are positive and negative points in favour of each option. The NHS-led option would be politically popular and help to fulfil the oft-repeated aim of a primary care-led NHS. This was essentially the course recommended by the Royal Commission on long-term care. The downside is that charging issues at the boundary (eg would nursing care in the community be charged for?) would be further highlighted. The most obvious solution - bringing all nursing (and personal?) care under the NHS - would also have a very significant cost to the public purse.

The local government option would build naturally on the 1993 Griffiths reforms and have the benefit of giving a stronger role to directly democratically accountable organisations, reversing an unpopular centralisation of power during much of the 1980s and 1990s. Many local authorities are keen to take on this role, citing the fact that the first health authorities were local authorities. However, a key problem here would be the perceived weakening and fragmentation of the NHS, together with an implicit extension of means-testing unless existing LA charging arrangements were changed. Making LA's responsible for long-term care would also create an even sharper boundary between acute and non-acute care, since the former would need to stay within the NHS under any scenario. Finally, it also goes against the grain of the development of 'Intermediate Care' services under NHS control and therefore free at the point of use to users.

The separate agency option would set up a 'delivery agency', which would operate between the 'vertical channels' or 'silos' of health care, social services, housing, etc. It would need to have a devolved budget, clear tasks and a chief executive who would be accountable for delivering its objectives. The problem would be how a single agency (or plural agencies) would interact with existing planning and delivery structures such as primary care groups and community mental health teams. There would also be professional accountability issues to be overcome - such as NHS

doctors working for local authorities.

## **A comparison between UK and US service delivery structures**

Whereas in the USA, HMOs integrate the financing and provision of medical care - but crucially not social care - in the UK, four separate organisations: the Treasury, health authorities (and, for social care social services departments), primary care groups and NHS Trusts perform this function. What is lacking in the UK is an equivalent body to the HMO to pull services together.

A comparison between the UK and USA health care structures looks as follows:

FUNDERS	TREASURY
HMOS	HEALTH AUTHORITIES
PRIMARY CARE	PRIMARY CARE GROUPS
HOSPITALS	TRUSTS

Such an organisation or agency would be able to have a coherent joint investment plan, but could delegate performance to the local level. The advantage of delegating delivery to a separate agency is that it would get round the problem of central departments (eg Home Office and DH) not talking to each other.

### **4.4 Finance and Funding Issues**

#### **4.4.1 General funding issues**

**"Generally speaking ... the promise of more efficient, faster health care has not been reflected in lower health expenditures.... support available to older people in the community care sector has not been expanded with the savings achieved from shorter hospital stays - the money has been retained in the hospital care system."** (John McCallum in Health Sector reform in Australia and New Zealand, ed A Bloom, 1999).

### **Should policymakers be worried about the costs of aging?**

The short answer is: no, not unduly. The health care costs of aging are unlikely to be a major source of fiscal pressure in the next 20 to 30 years in most of the countries examined. Inappropriate use of services and unnecessarily costly or acute care settings are likely to be a greater concern for policymakers and funders in the short to medium term than the expectation of care cost increases in later years of life, particularly if the cost burden is shared between public and private sectors, eg through moderate use of co-payments (see Section [2.2.2] below).

The central projection of UK care costs, reported by the Royal Commission, shows

that the costs of private and state paid formal care for older people could rise from £11 billion or 1.6% of GDP in the mid-1990s to around £20 billion (1.6% of GDP) in 2021 and £28 billion (1.8% of GDP) in 2031. In other words, though care costs will rise by around 2.5% in real terms, the burden on society of long-term care is only likely to rise by a few tenths of one per cent of GDP.

Leaving aside the fact that focusing the debate on the 'costs' of caring for older people leads people to ignore the benefits to society of having its elders, the methodology of assessing and projecting these costs may also be flawed and over-estimate the likely costs. In the aging literature, there is a debate about whether costs should be projected using a 'years to death' method (which assumes that most of the costs of aging fall in final years of life) or on a 'years from birth' basis (which assumes that as people grow older they consume more health care). The latter is the basis for most cost estimates including those quoted for the UK above.

OECD modelling of health costs associated with aging using these different methodologies shows that using 'years to death' results in significantly lower, and even less politically alarming, estimates of costs. Professor John McCallum (in 'Health Sector Reform in Australia and New Zealand', ed Bloom A, 1999) refers to evidence that the 'years from birth' method may overstate Australian per capita health spending by as much as 4% to 8% by the year 2030.

It is widely acknowledged that most health costs in an individual's lifetime are accrued in the latter part of their lives. Australian evidence shows that about one third of all health care costs are attributable to the 10% of the population who are over 65. As the percentage of the population over 65 grows in developed countries (and this is a phenomenon that principally affects developed countries), so care costs can be expected to rise faster in real terms. But the aging effect is far from being the only - or even the most important - factor in increasing health spending. Other factors include the fact that expectations of health care (by healthy people) may lead to greater use of services and over-servicing by professionals to increase their income (eg through drug prescribing or elective surgical procedures).

### **Is more holistic/integrated care likely to be self-funding?**

Academic research warns against an over-optimistic view that integration initiatives will self-fund new services through 'savings' when an existing service is substituted for a lower cost alternative. Experience shows that new service funding helps to facilitate integration - and in this area, as in others, helps to 'oil the wheels' of new practice. Precedents for such 'new' funding include US Social HMO funds from member premiums and the 'extra' money received by HMOs for frail clients; generous Medicaid capitations for the PACE programme and new service funds for the UK managed care experiments (Kent CCP et al).

Pump priming is also necessary, although funders may have the expectation that some - though not all - of this money can be recouped later. Successful integration projects have generally been helped by significant start-up grants including in the US, the first round of social HMOs, PACE, the Wisconsin Partnership and Minnesotan experiments, and in the UK special transitional grants for coordinated care projects and total purchasing pilots.

As integration projects move beyond the demonstration stage, policymakers must also think about earmarking funds for their continuation - from within existing resources if necessary (forcing economies elsewhere) - so that the benefits of the projects are not ignored in the face of routine funding constraints. Leutz remarks in his survey of UK and US integration experiments that: *"failure to consider these [replication] costs, which could legitimately be considered long-term investments, is a typical shortcoming of public initiatives which are often strapped for cash and may not recognise the new management, training and supervision models... required."*

He goes on to note that, unless the start-up and continuation costs are recognised, integration may not occur, staff may not participate in planning, and smooth support systems will not be developed.

#### **4.4.2 Public and private funding streams**

### **Charging issues**

**"The system at the moment helps people who are poor, demands that people of modest means make themselves poor before it will help, and affects people to a lesser extent the richer they are and better able to afford the sums required. This seems strangely inconsistent..." (UK Royal Commission Report on Long Term Care, para 4.16).**

The debate in many countries on health care is often governed by the perception of insufficient funds being available for treatments. This pressure is particularly strong in countries, eg the UK and Scandinavia, where the public sector shoulders the vast majority of the health bill. Yet resourcing constraints are unlikely to go away given constrained budgets in the public and private sectors and the cost pressures from demography, medical technology and R&D as well as pressures from the demand side from better informed consumers and rising expectations.

The question lurking behind this important debate is how much society should be expected to pay from its available resources to give an individual the chance to benefit from a given treatment. This is the cutting-edge of the 'rationing' debate as it affects purchasers, clients and their families. At the moment in the UK, out of a total public cost of long-term care of around £7.5 billion, around £200 million is being recouped from charges. Leaving aside the health care element of that expenditure, which is free to consumers, this implies that £1 is raised for every £25 spent on publicly subsidised care. This seems pretty small for a means-tested service.

If it is accepted that long-term care costs should be shouldered by both the public and private sectors, more effective use needs to be made of charges and co-payments. One option, which has a number of attractions, is to rely more on selective charging and patient co-payments. In a world where the publicly (or employer) provided health system is unlikely to meet all the health needs of all older people, some treatments will not be available through the publicly funded system (in Europe or Australasia) or through Medicare, HMO or employer-sponsored plans (in the USA). Apart from the pragmatic merits of greater public-private cost sharing in helping to fulfil more marginal demands, cost sharing has the merit of sending the

right incentives on the consumption of health care in a world of constrained funding.

However, relying more heavily on patient cost sharing has a number of political and economic risks. Since earnings and health care are unevenly distributed, cost sharing raises the issue of equity. It is unacceptable to current political thinking, in at least Northern European countries, to exclude people from most health and social care services on the grounds of ability to pay. In the US, the equity issue is reflected in concern about the growing numbers of uninsured and under-insured as premium contributions and out-of-pocket costs grow.

Most older people are asset-rich and income poor. The Royal Commission cited figures which show that the majority of people over 75 years of age in the UK have assets below £40,000 (\$60,000) with mean incomes of £95 (\$140) per week. Although people of retirement age today have more disposable income than their predecessors, those needing serious long-term or chronic care find they very quickly run down their assets (care costs for the chronically ill can easily exceed £20,000 a year) and may have to sell their home.

The UK Royal Commission eloquently set out the arguments for risk-pooling, which are persuasive. The challenge now is to find acceptable ways for people to access the wealth locked up in their assets (homes, pension funds, etc) and use the monies released to complement existing public LTC funding. Two ideas (space prevents these ideas being more than sketched out here) which could be explored are:

- **creating a national fund (perhaps administered privately) to pool risks** between the healthy, frail and those who need long-term care, perhaps learning from German experience of setting up an LTC Fund. Ideally, by careful design, such a scheme would not add to public expenditure;
- **a mechanism to refinance the domestic housing market.** Given that most older people's wealth is tied up in their own homes, a financing vehicle could be set up which would re-mortgage domestic property, offering people a bond which paid interest in return for a share in the appreciated value of the home when the property was sold or disposed of.

#### **4.4.3 Pooled budgets**

### **Is fund pooling required or is 'joint working' enough?**

In the UK, it is clear that the policy aim is to make health and social services staff work closer together in commissioning, purchasing or providing a specific service. This is clearly better than current patchy practice. Information-sharing, joint protocols and a greater willingness on the part of different services to work together are positive steps towards a more cohesive service. But the question is: is collaboration enough? If not, is a single budget or formal fund pooling required?

Very few people believe that **a single budget** within one department or organisation is the only answer to high quality long-term care, although for a small group - the disabled elderly with multiple, complex and chronic care needs - single budgeting arrangements are probably best. The solutions adopted in England and Scotland for

people with learning disabilities, where funding has been successfully integrated and 'dowries' given to individuals to move from residential to homely environments, has generally worked well.

Various countries are experimenting with formal **fund pooling**, which goes one step further than UK policy. This is intended to allow various services to pool their funds and allow a more rational way of allocating (some might say rationing!) services across all clients. There is emerging evidence that pooling care budgets, coupled with a separation of assessment, care package formulation and service delivery, is more cost-effective and can achieve higher quality care than collaboration on its own.

Emerging evidence from the Australian coordinated care trials is that fund pooling is far from easy. There is a steep organisational learning curve. It usually implies costly adjustments to financial allocation mechanisms, requires consistent IT systems to be in place for pooling to really work effectively, and implementation involves a good deal of negotiation among participating agencies. Powerful existing players, eg hospitals, do not like having their funding threatened or 'pooled'.

However, many think that **formal care coordination**, where a coordinator has access to different funding streams as in the Australian coordinated care trials, is helpful. This model seems to work by getting incentives right, enabling complementary care packages to be provided. It also has the helpful by-product of reducing the tendency for information to be duplicated or get lost in the system.

#### **4.4.4 Direct payments: lessons from abroad**

One of the more hopeful areas of international innovation is the idea of 'consumer-directed care': substituting a cash sum for formal services. The unifying principle is that individuals have the ability to make choices that work best for them. A number of US states, including Michigan, Wisconsin and Colorado, are also currently using state funds to include direct payments into their LTC systems. The model, or a variant of it, is also being tried in the Netherlands, Germany and Austria.

The US is running experiments called 'Cash and Counselling' in which personal care services are provided by home care workers selected, trained and supervised by the consumer. In these pilots, individuals can use cash payments to purchase whatever support they need, for example home care services from a private agency, a place at a day care centre, remunerating a friend or a relative to care for them, or they may use the money to make home modifications or buy assistive devices, such as a microwave or access to an internet home shopping service, which may limit their need for future care.

An evaluation of the Californian programme showed that, overall, clients preferred the consumer directed care model, although the provider agency model seemed to satisfy clients with relatively moderate needs. The interpersonal and other benefits of receiving services from a family member seemed to outweigh any possible shortcomings in technical skills. However, problems with the model include the deadweight cost of remunerating previously unpaid family labour and the possibility of funds being misused. The Israeli experience, however, shows that care needs to

be taken with substituting cash payments for care-in-kind.

#### **4.4.5 Getting incentives right**

In long-term care, limited public funds and value for money is best served by getting people rehabilitated as quickly as possible. This is likely to make best use of taxpayer funds, even if rehabilitation implies an up-front investment. The funding system needs to work together with methods of care delivery to encourage individual independence. This tends to suggest forms of capitation funding or at least a regime where 'the money follows the person'.

Bulk funding of health and social care agencies has administrative advantages and allows agencies to optimise and cross-subsidise their services, but gives little protection against over-servicing. However, with clear statements about coverage, prices set low enough to encourage agencies to seek co-payments and a consumer-based monitoring mechanism (and less use of 'snoopers') allied to fines and prosecutions, bulk funding could be an efficient funding mechanism.

The current LTC systems in most countries are clearly biased towards residential care, which is not necessarily consistent with providing best value and goes against all the evidence on the preferences of the elderly themselves. But, encouragingly, several American states (Oregon, Wisconsin, New York), Australia and the Dutch have made significant progress in moving away from a residential care model through determined measures to 'level' the incentives between residential and domiciliary care.

In the past in the UK, residential care was often the lowest cost option for local authorities since there are benefit incentives to using private care homes and disincentives to using publicly run facilities as part of Income Support - the Residential Allowance - was not available to those in local authority run homes. The current UK system still provides an incentive to get people into (non-NHS) institutional care as fast as possible.

The effects arising from perverse incentives and poorly designed systems can be extremely costly. The introduction of a mechanism in the UK which allowed people to have their welfare (income support) payments passed directly on to residential and nursing care providers to pay for their care led the costs of residential care to escalate from around £350 million in the mid 1980s to £2.5 billion by the early 1990s and total net PSS costs to increase by over 90% in real terms.

The incentives to cost shift from one funding body to another which arise out of ill thought through care boundaries, eg between the NHS and local authorities in the UK, Medicare and Medicaid in the US and Federal and state-sponsored expenditure in Australia, usually results in sub-optimal care. In the worst cases, it can result in premature hospital discharge and death or painful and clinically unnecessary trips to hospital to avoid charges for care in a particular location.

In contrast, getting incentives right can save greatly on costs. A good example is the introduction of the compulsory German long-term care insurance scheme with an

incentive to take cash over formal care reduced welfare assistance payments (for help with care costs) by over DM10 billion since 1995.

### **Can we devise outcome-based funding models?**

The history of funding social programmes can be seen as a move from input-based - eg paying on the basis of beds or doctors - to output-based - payment based on lengths of stay or treatment, eg inoculations, etc, carried out - funding. We now urgently need to move beyond funding outputs, which reward one activity over another, to person-centred outcome-based funding models. Some encouraging work is being done in the US and UK on these issues, eg by PSSRU collaborating with colleagues in Boston.

But examples of an outcome-based system are few and far between. Most systems still specify the achievement of given outputs at best. Many administrators and policymakers still confuse 'output' and 'outcome' based measures. Outcome-based measures are plagued with two main problems: first, which outcomes do you specify? - quality of life, independence, life expectancy, integration into the community, years free from disability, etc; second, measurement problems, namely how do you measure 'quality of life' or 'independence'?

The answer seems to lie in the notion of person-centred care itself. The goals for an individual's care programme need to be determined by the client and a measure agreed to assess progress against this goal. While this is admittedly subjective, most individuals are able to assess their quality of life providing the question is framed and asked carefully.



## 4.5 Best Practice and Policy Lessons from Other Countries

### **4.5.1 An overview: a best practice checklist**

There is a large, and perhaps surprising, degree of consensus of what represents best practice in long-term or chronic care. Much of this best practice philosophy also applies to other chronic care services, eg mental health care. The main ingredients of best practice which were recommended by academics, policymakers and practitioners in the USA, Australasia and Europe can be divided into process and service delivery categories.

As far as **process** is concerned, the following are deemed to be crucial:

a clear national strategy for delivering chronic/long-term care;

good information, ie up-to-date records, pooled data sets & trackable patient/client data;

early intervention (certainly before entry into acute care) ideally based on an individual 'wellness' programme;

multidisciplinary assessment, which assists in delivering patient-centre care;

integrated funding streams, whether mandatory or voluntarily instituted.

In terms of **service delivery**, the following have been found to be important:

a clear geographic area for delivering services;

multiple entry points into health/social care system;

education, assistance and prevention - giving the client information on risks and services, one phone number to call and build community support capacity;

holistic care, eg on health side, care is best overseen by a geriatrician;

GP involvement. GPs need to be involved, empowered and skilled up.

Such a list, appropriately scored and weighted to take account of national priorities and preferences might be useful as a simple benchmarking tool for delivering 'best practice' care.

### **4.5.2 Modernising government**

Central government departments do not communicate well anywhere. One possible answer is to amalgamate ministries as, within the limits of technology and scale, communication within departments is usually better than communication between departments. Until recently, Australia had a combined Department of Health & Family Services (though this has since been separated into a Department of Health

& Aged Care and a Department of Family Services).

The State of South Australia has gone further still and has a department combining health, housing, family and community services. Australian ministries are frequently re-organised, but this experience suggests that health, social care, housing and community services can be administered within one department.

However, 'mega-ministries' are often unwieldy and there are struggles for influence and funding within departments, where smaller, weaker, policy areas, eg with the department of health - health promotion, older people or mental health areas can lose out.

### **4.5.3 Building on UK best practice**

There are a number of areas where the UK is doing leading edge work, but could build on its own good practice:

capacity needs to be built in the community to enable people to help themselves. Health Action Zones in the UK are doing some very interesting work in encouraging individuals from deprived communities to take more active roles in the community. A big stumbling block is the benefit system, which still makes it difficult for people to combine work and other interests. In long-term care, international evidence supports the view that respite care has a crucial role to play in allowing people to preserve their autonomy;

NHS trusts and local authorities could become better purchasers. Besides capitated funding and comprehensive care assessment, delivery and funding structures, it is vital to help consumers become informed purchasers of health and social care. Organisations like the Audit Commission in the UK and the Foundation for Accountability in Oregon in the USA are doing a lot of useful work in this area;

build on successful initiatives by incorporating pilot monies into mainstream funding where this is merited. Recent 'winter pressures' money has been used very constructively to address structural issues, eg through funding joint teams for care for the elderly. The benefit of this funding will be lost if it is not incorporated into recurring funding;

wasteful structures and practices could be reduced. The UK has cut average hospital lengths of stay markedly in the last 10 years. But, in the face of evidence that people still stay too long in acute care, this could probably be cut still further - perhaps by as much as 20% in the short run. Care, though, needs to be taken to ensure that older patients have their need for social care addressed when they move into the community. More attention could be given to reducing over-medication and the duplication of care by different professionals.

## **ANNEXE 1: POLICY DEVELOPMENT IN THE UNITED KINGDOM**

There have been significant developments in UK policy towards Health and Personal Social Services over the last two years. The Department of Health (DH) 1998 Discussion Document *Partnership in Action* stated that: "The Government's strategic agenda is to work across boundaries to combat social exclusion, encourage welfare to work, tackle inequalities between men and women and improve health in local communities."

### **NHS White Paper and 1999 Health Act**

Concepts of effectiveness, managed care and a 'third way' underpin recent initiatives. Early after the election of the Labour Government in 1997, a National Health Service (NHS) White Paper (*The New NHS: Modern, Dependable*), was published which set out a new policy orientation towards 'integrated care' and moved away from the philosophy of an 'internal market' for health services. The White Paper also encouragingly set out a 'Third Way' which aimed to: "build on what has worked, discarding what has failed" and "provide a system based on partnership and driven by performance".

Both the NHS White Paper and a companion Green Paper: *Our Healthier Nation: A Contract for Health*, also published in 1997, laid an emphasis on the need for effective working between the NHS and local authorities. This emphasis is underpinned by a new duty of partnership and set in the context of a duty on health and social agencies to draw up a *local* Health Improvement Plan (HimP).

### **NHS White Paper policy commitments**

The NHS White Paper noted: that "people with multiple needs were passed from pillar to post inside a system where individual organisations were forced to work to their own agendas rather than for the needs of individual patients". It had four policy commitments of direct relevance to the boundary issues between health and social services which affect the elderly:

the NHS should work more in partnership by breaking down organisational barriers within the NHS and by putting the needs of patients at the centre of the care process. The NHS would remain a universal health service available on the basis of need not ability to pay;

links between health and local authorities would be strengthened;

GP-led primary care groups would take responsibility for commissioning, ultimately controlling a single unified budget, and would work closely with social services;

new evidence-based National Service Frameworks would be set up to ensure access to services and improved quality of care.

The White Paper stated that the new NHS would build on its successes in:

- separating the planning of hospital provision from provision;
- maintaining the central role of GPs and community nurses;
- decentralising responsibility to hospital and primary care managers.

It would, though, discard the failures due (in its view) to excessively fragmented services. The White Paper identified the following problems and proposed solutions:

<b>Problem</b>	<b>Proposed Solution</b>
Fragmentation	Institute Health Improvement Plans (HIMPS)
Unfairness	Treat patients according to need alone
Excessive competition	Find mechanisms to share best practice
Narrow efficiency measures	Devise broader measures of performance unifying budgets where possible
Instability and secrecy	Allow longer terms contracts and funding agreements, promote openness and public involvement

A key part of the 1999 Health Act built on the NHS White Paper proposals and gives health and local authorities (social services departments) new powers to:

enable health (health authorities or primary care trusts) and social services authorities to pool their resources into a joint budget which would be accessible to either party to commission and provide services;

enable one authority to transfer funds and delegate functions to the other to take responsibility for commissioning both health and social care;

allow one organisation to provide an integrated service, for example an NHS Trust or primary care Trust might provide social services or a social services provider could to provide a limited range of community health services.

It was decided that these powers should be permissive - in other words it will be up to health and local authorities to decide between themselves which arrangements if any will be most helpful to their joint working.

The new Labour Government which came in 1997 was committed to improving the worsening situation of inequity between regions and social groups. A whole raft of new initiatives were set up under three broad headings - setting standards, delivering standards and monitoring standards:

### Setting standards

the National Institute for Clinical Excellence (NICE) was set up to write and propagate clinical guidelines. All prescribing advisory bodies were amalgamated into one organisation;

National Service Frameworks, not dissimilar from New Zealand planning documents, were to be drawn up based on reviewing international evidence on what works.

### Delivering standards

the concept of professional self-regulation was used to launch confidential enquiries into homicides and suicides;

clinical governance was used to reverse the situation where the NHS had national and regional financial targets but few clinical care standards and to come up with a plan to fund continuing clinical education;

more attention given to life-long learning.

### Monitoring standards

Elements of this included:

a Commission for Health Improvement;

National Performance Frameworks;

a national survey of consumers to help remedy the dearth of consistent national information.

### 1998 Social Services White Paper

Following the broad framework established by the NHS White Paper, the Government turned its attention to personal social services (PSS). A Social Services White Paper (*Modernising Social Services*) was published in November 1998 which picked up the themes of partnership and performance. It set specific objectives for adult and children's services and aimed to improve management through a new performance management framework with appropriate indicators.

Several specific developments and policy initiatives affecting social services are worth mentioning in some detail:

the Comprehensive Spending Review of departmental spending allocated PSS a real increase of 3% a year. Quite a lot of this was given in the form of specific grants;

Ministers spoke about "breaking down the Berlin Wall" between health and social services;

National Priorities Guidance was issued to individual local authorities;

Legislation was formulated and has been approved which will permit pooled budgets as from April 2000;

it was recognised that Health Improvement Programmes required joint planning at the local level;

a new Chief Inspector was appointed and a Commission for Care Standards was set up which will take over the role previously performed in this area by the Social Services Inspectorate.

## **ANNEXE 2: COST DRIVERS IN LONG-TERM CARE**

Detailed financial issues concerning funding models, charging regimes and financial incentives are treated in a separate financial issues section within this section of the report. One issue, though, deserves up-front analysis - namely does better long-term care imply that long-term care expenditure should rise not just absolutely but as a proportion of GDP?

In all countries, health and social care spending on the elderly is rising - often to the dismay of governments and national Treasuries, who see many other pressing calls on the public purse.

The key factors which are likely to drive long-term care spending are:

the growing numbers of the elderly, both in absolute terms and as a proportion of the overall population in nearly all developed countries (see Annexes of country chapters for country-specific information);

the increasing health care cost of one episode of care for the elderly, who already cost several times the average cost of an episode, mainly due to the complexity of their medical care needs allied with the rapidly rising real cost of advances in medical technology;

the pressure to improve the quantity and quality of care services in the face of the recognition that there is a large volume of unmet need (eg for respite care) and that skill levels and client interactions are sometimes sub-optimal;

perverse incentives in the care system. These vary depending on the system in question but typically lead people to make excessive use of free or subsidised services and receive unnecessarily expensive or redundant services. Examples include: seeking publicly subsidised (and relatively expensive) health care in the place of potentially cheaper (but usually means-tested) social care, taking up unnecessary but free services, eg some medical tests in a fee-for-service system or seeking institutional as opposed to domiciliary care if there is greater public support for care in that setting.

