RESIDENTIAL CARE IN KENT

A REVIEW BY A SELECT COMMITTEE APPOINTED BY THE SOCIAL CARE AND COMMUNITY HEALTH POLICY OVERVIEW COMMITTEE

PARTS I AND II

CHAIRMAN: MR M J FITTOCK



DECEMBER 2003

FOREWORD TO THE SELECT COMMITTEE REPORT ON RESIDENTIAL CARE AND THE ALTERNATIVE MODELS OF CARE FOR OLDER PEOPLE WITH MENTAL HEALTH NEEDS

On behalf of the Select Committee I am pleased to present the final report on residential care in Kent. This report concentrates on the issues surrounding services for older people with mental health needs (OPMHN). This follows on from the report on Domiciliary Care and that of Nursing Home Care, published by Kent County Council in February 2002 which recommended a separate review of residential care.

Through meeting stakeholders from the NHS, social services and voluntary sector it was apparent that there was a high degree of consensus over the perceived problems and gaps in service provision for OPMHN to be addressed. Key over arching issues were the

- limited availability of OPMHN community/home based support leading to delayed transfers and early admission into residential care settings
- limited availability of respite care for carers , particularly at night
- lack of information and support at time of diagnosis for carers and OPMHN
- limited access to recuperative care services for people with dementia or mental health needs
- the importance of dementia awareness training for staff in all care settings, including residential, sheltered housing and care at home.

The greater provision of community care to enable independent living at home or in a sheltered setting could make a major difference to both the quality of life for individuals with dementia and their carers and extending their independence.

Throughout Kent there are many new initiatives and developments in care provision for the elderly, established within considerable resource restraints. These should also reflect the needs of OPMHN. There are models of care that provide alternatives to residential care and a greater amount of care could take place at home within current resource levels.

The residential care report received unanimous cross party agreement. Finally, I would like to thank my colleagues on the committee, the staff who supported the work, and all those who gave up their time to give evidence.

Mark Fittock, Chairman of the Select Committee

CONTENTS

| <u>PART 1</u> Executive Sum | | GE 4 |
|--------------------------------|---|---------|
| PART 2 | | |
| Chapter One | Introduction to the Social Care and Community Health Policy Overview Committee and the Policy Overview Process | 8 |
| Chapter Two | Older People and Mental Health Needs Types and effects of dementia Depression | 10 |
| Chapter Three | National and Local Policy Context The National Policy Context The Local Policy Context | 13 |
| Chapter Four | Demographics The National Picture Demographic trends and prevalence of dementia Prevalence of Depression Prevalence of dementia and depression among elderly people in Black and ethnic minorities | 20 |
| Chapter Five | Residential Care Homes Reasons for admission to residential care homes Future demand for residential care Fair price for care and provider viability Fee levels Capacity and provision of specialist residential care beds Recruitment and retention Care staff qualifications and training National Care Standards Commission (NCSC) Affordable Key worker housing Activities Transfers to different care homes Service model/built environment Support of Care Homes/Community Nurse support Out of area placements Development Planning The future | 25 |
| Chapter Six | Care at Home Prevention and health promotion Low level preventative services Domiciliary services RED – Rural emergency and hospital discharge service | 40 |

- Intermediate care
- Rehabilitation and recuperative care
- Support at home service/Rapid response service
- Community and equipment services
- Care and repair services and Home Improvement agencies

49

67

74

76

79

• Befriending services

Chapter Seven Carers, Respite and Day Care

- Strategy for Carers
- Carers needs
- Information needs
- Admiral Nurse service
- Communication
- Respite care
- Day Care
- Effect on carer of someone going into care
- Titles of carers

Chapter Eight Sheltered Housing and Extra Care Sheltered Housing 58

- Extra Care Sheltered Housing in Kent
- Extra Care Sheltered Housing for OPMHN
- Scheme managers/scheme wardens and staff issues
- Social isolation
- Rebuild, refurbish or modernise buildings
- Image and difficult to let units
- Support schemes
- Owner-Occupiers
- Rural area provision of Sheltered Housing
- Fire safety
- Planning and development
- Care communities

Chapter Nine Assisstive Technology

- The policy context
- Assistive Technology in Community equipment services
- Community Alarm services and Telecare
- Care Homes and Sheltered Housing
- Smart Homes
- Demonstration of Technology
- Lifetime Homes

Appendices

| Appendix One | List of Witnesses |
|--------------|---|
| Appendix Two | The four stages of dementia and Intervals of care |

Glossary of Terms Bibliography

PART 3 Evidence: Summary of Select Committee meetings (separate document)

EXECUTIVE SUMMARY

In June 2003, a seven Member Select Committee was set up to carry out a review of residential care homes and the alternative models of care for older people with mental health needs. The Members of this Select Committee were Mr M Fittock (Chairman); Mrs J E Butcher; Mr A Chell; Mrs M E Featherstone; Mrs V Dagger; Mrs J Newman; Mr M V Snelling. The Select Committee heard evidence from a number of witnesses involved in the delivery or receipt of services for older people with mental health needs (OPMHN). These included officers from the social services directorate; care providers from the in-house and independent sector; informal carers and voluntary organisations. A complete list of the witnesses who gave evidence to the Select Committee is shown in Appendix 1.

The Terms of Reference for the Select Committee were:

"To consider the role of Residential Care for older people and explore alternative care models, with particular emphasis on care of older people with mental health needs (OPMHN)."

The aims were to:

- a) Identify the issues of residential care provision for older people in Kent and how these impact on provision of Residential Care for OPMHN.
- b) Gain an understanding of the National, Regional and Kent approach to residential care of older people and prevention/support services.
- c) Seek a balanced range of views from key Kent bodies, experts, service users, carers and pressure groups.
- d) Gain an overview of the range of approaches to the care of older people with mental health needs including Residential Care, Prevention services (e.g. Recuperative Care), Sheltered Housing.

There are several reasons for carrying out this review. In recent years mental health care and the prevention of avoidable admissions to long term care have become national priorities. The focus on greater independence and enabling clients to remain at home for as long as possible are also a high national and local priority, and are playing an increasingly important role in shaping efficient, person-centred community care services. The rising demographic pressures and the prevalence of dementia have emphasised the need for services to meet the needs of OPMHN and provide alternatives to long term residential care. In addition the care home sector is going through a period of immense change with the implementation of the National Minimum Standards and new regulation, and market pressures, set in a climate of difficulties in the recruitment and retention of care staff. Care staff also need a greater understanding of the needs of OPMHN and appropriate training to enable them to work more effectively with and deliver the appropriate levels of care to meet the needs of OPMHN. Although there will always be a need for some residential care home provision, particularly for the most dependent, there is evidence that OPMHN can be maintained at home and many older people are admitted unnecessarily to residential care. The report discusses government policy on residential care provision for older people and OPMHN and how this is translated in Kent and the availability and appropriateness of alternatives to long term residential care for OPMHN. The review has looked at four main areas namely Support at Home, Informal care, Sheltered and Extra Care Sheltered Housing and Assistive technology. The main body of the report is divided in to nine Chapters. The recommendations to the Council are:

Residential Care - (Chapter Five)

- 1. SSD need to assess and quantify trends, costs and demand for residential care for OPMHN over the next 10 years. (5.19)
- 2. SSD should develop a plan to identify the trends and how demand for residential care for OPMHN can be met over the next 10years and how provision can be encouraged where appropriate. (5.19)
- 3. SSD need to encourage ways to provide progressive training in partnership with Health, private care providers and voluntary organisations, and research further funding streams. (5.29)
- 4. SSD need to lobby national and planning authorities for the recognition of care workers as key workers. (5.32)
- 5. SSD need to create a plan to encourage the development of activities to meet the needs of OPMHN and the individual. This could include partnerships with Adult Education and voluntary organisations. (5.35)

Care at home - (Chapter Six)

- 6. The opportunity for recuperative care should be extended and encouraged for all older people with mental health needs either as a separate service or within mainstream service. (6.16)
- 7. SSD should ensure recuperative care services are developed equitably across the county, using the private and voluntary sector if appropriate. (6.16)
- 8. SSD to explore the opportunity to extend and develop current care and repair services to the wider community as appropriate in partnership. (6.28)
- 9. SSD should encourage the establishment of partnership plans to provide dementia training that would assist Home Improvement Agencies and care and repair teams work effectively with OPMHN. (6.29)
- 10.SSD should encourage the development and/or establishment of schemes focusing on social inclusion of OPMHN and their carers where required. (6.30)
- 11.SSD need to consider the capacity needed in all services contributing to the home based support model to ensure that people with dementia can access timely, responsive and effective care. (6.30)

Carers, Respite and Day care - (Chapter Seven)

- 12. As a high priority SSD should develop both a carers strategy and a strategy for carers of people with mental health needs including dementia. (7.2)
- 13.SSD to actively promote the use of social workers with training in mental health needs to support local GP practices. (7.6)
- 14.SSD should extend and encourage further provision of the range of respite care provided in a variety of settings. (7.17)
- 15. SSD need to encourage residential care home providers to involve residents with dementia and their relatives/informal carers in the care practice and the management of residential care homes. (7.25)
- 16. SSD should encourage the involvement of relatives of OPMHN in care role in ways that are appropriate to the needs and circumstances of individual residents and their families. (7.25)

Sheltered Housing and Extra Care Sheltered Housing - (Chapter Eight)

- 17. The Sheltered Housing strategy and its recommendations should be endorsed, supported and encouraged. (8.3)
- 18.SSD (in partnership) should raise the profile and improve the image of sheltered housing and extra care sheltered housing. (8.16)
- 19. SSD should encourage the provision of sheltered housing options accessible to owner-occupiers (and owner-occupiers with MHN) and encourage the involvement of private sector/developers and the development of split tenure or mixed tenure sites to meet local needs. (8.21)
- 20. SSD need the involvement of the fire brigade in new build development of sheltered housing schemes as part of the emerging joint initiatives. (8.24)
- 21. The contribution of land from KCC for appropriate schemes should be encouraged and SSD and the Property Group capital receipts team should be proactive to ensure identification of potential sites. (8.27)
- 22. SSD should use influence to encourage developers/planners to include lifts in two/three floored schemes and encourage 'building for life building for all' principles. (8.28)

Assisstive Technology – (Chapter Nine)

- 23. SSD should consider further the use of new technology to support OPMHN within the various care settings and look to develop this area in partnership where appropriate. (9.17)
- 24. SSD should consider extending the use of technological services to assist the care of OPMHN at home and in sheltered housing. (9.20)

- 25. SSD should provide information for users, carers and professionals on the possibilities of technological services as they are developed across Kent. (9.20)
- 26. SSD to develop a county wide strategy for the use of assistive technology, including telecare in community care provision. (9.20)

Government policy has promoted both the importance of joint working between health and social services and the arrangements to enable closer working practices to develop more effectively in support of multi agency working. The NHS Act 1999 permitted pooled budgets, lead commissioning and integrated provision. The increase in joint working between health and SSD should lead to improvements in services for older people and older people with mental health needs and their carers.

The Select Committee highlighted the continuing importance of the developing agenda to work collaboratively together with the NHS to both deliver and develop services and acknowledged current developments and successful joint initiatives. The Select Committee recognised that some of the recommendations will require working in partnership with other key stakeholders including the NHS, and that this should build upon the good work already achieved.

CHAPTER 1: INTRODUCTION TO THE SOCIAL CARE & COMMUNITY HEALTH POLICY OVERVIEW COMMITTEE AND THE POLICY OVERVIEW PROCESS

1.1 Kent County Council is the democratically elected strategic authority for Kent. It has the broad power to promote and improve the social, economic and environmental well being of the area and has the statutory responsibility for the provision of a range of services. The Local Government Act 2000 laid out new procedures for the reform and modernising of local government. One of its main aims was to increase openness and accountability within local government, with local people playing a greater part in shaping and receiving better services. On 1st September 2001 Kent County Council adopted a new Constitution introducing a new political structure with a Leader and a single-party Cabinet taking most of the decisions previously taken by all-party service committees.

1.2 Under the new Constitution elected Members outside the Cabinet can contribute to the development of policy through the appointment of Policy Overview Committees, which focus on different services provided by the County Council. The three Policy Overview Committees help and advise the Council, the Leader and the Cabinet on the development of the Council's policies and review the Council's performance compared with objectives and targets.

1.3 The Policy Overview Committees have the power to set up smaller Select Committees to look in depth and review particular policy issues by way of topic reviews. The all party Select Committees are made up of Members from the different political parties proportional to the number of Council seats held by each party.

1.4 The Social Care & Community Health Policy Overview Committee (SCCH POC), considers various functions related to those managed by the Strategic Director of the Social Services Directorate. These may be issues relating to the introduction of new legislation, policies, or specific services that the SCCH POC consider need to be looked into at depth. In June 2003, a seven Member Select Committee was set up to carry out a review of residential care homes and the alternative models of care for older people with mental health needs. The Members of this Select Committee were Mr M Fittock (Chairman); Mrs J E Butcher; Mr A Chell; Mrs M E Featherstone; Mrs V Dagger; Mrs J Newman; Mr M V Snelling.

1.5 The Terms of Reference for the Select Committee were:

"To consider the role of Residential Care for older people and explore alternative care models, with particular emphasis on care of older people with mental health needs (OPMHN)."

The aims were to:

- e) Identify the issues of residential care provision for older people in Kent and how these impact on provision of Residential Care for OPMHN.
- f) Gain an understanding of the National, Regional and Kent approach to residential care of older people and prevention/support services.

- g) Seek a balanced range of views from key Kent bodies, experts, service users, carers and pressure groups.
- h) Gain an overview of the range of approaches to the care of older people with mental health needs including Residential Care, Prevention services (e.g. Recuperative Care), Sheltered Housing.

1.6 There are several reasons for carrying out a review of residential care homes and the alternatives for older people with mental health needs. First of all, increasing independence and enabling clients to remain at home for as long as possible is a high national and local priority, and is playing an increasingly important role in shaping efficient, person-centred community care services. Structured services tailored to the needs of older people are central to the successful implementation of national and local care policies in meeting the needs of an ageing population. Secondly, the care home sector is going through a period of immense change, as is the social care sector. The transition is due to the implementation of the National Minimum Standards and new regulation, set in a climate of increasing difficulties in the recruitment and retention of care staff who carry out more complex tasks than ever before. Thirdly, although there is a need for some care home provision, particularly for the most dependent, there is evidence that OPMHN can be maintained at home and many older people are admitted unnecessarily to residential care.

- 1.7 It was decided to focus on four models of care:
- Support at Home
- Informal care
- Sheltered and Extra Care Sheltered Housing
- Assistive technology

The Select Committee heard evidence from a number of witnesses involved in the delivery or receipt of services for older people with mental health needs (OPMHN). These included officers from the social services directorate; care providers from the in-house and independent sector; informal carers and voluntary organisations. A complete list of the witnesses who gave evidence to the Select Committee is shown in Appendix 1. The Select Committee took evidence during July 2003.

CHAPTER 2: OLDER PEOPLE AND MENTAL HEATH NEEDS

The two largest groups of people with mental health needs over the age of 65 are those with dementia and those with depression.

2.1 <u>Types and effects of dementia</u>

Dementia is a term used to describe different diseases and disorders that affect the brain and are usually progressive and incurable. There are over 100 different types of dementia. Alzheimer's disease, vascular dementia and dementia with Lewy Bodies are the most common. It is estimated that Alzheimer's disease accounts for 55% of all cases of dementia; Vascular dementia accounts for 20% of cases, caused by a series of tiny strokes and dementia with Lewys bodies 15%.¹ Dementia can be classified as minimal, mild, moderate or severe. An explanation of the differences at each level are defined in Appendix 2.

2.2 The loss of functioning depends on which area of the brain has been affected. While each person will experience dementia in their own way symptoms typically include memory loss, confusion and difficulties with speech and understanding. As the dementia progresses, the structure and chemistry of the brain becomes increasingly damaged and the person's ability will gradually decline. As people age a small amount of forgetfulness, confusion and loss of short term memory are normal and developing dementia is not an inevitable consequence of old age.¹ Dementia is rare before the age of 65, but the incidence rate of dementia does increase sharply with age. This is discussed in Chapter 4.

2.3 It is important to note that dementia progresses and affects everyone differently but typically can result in:

- difficulties in communicating, such as finding the right words or understanding. The person with dementia may retain the ability to communicate feelings, needs and preferences through facial expression and body language.
- problems with short term memory, for example forgetting the names of friends or family and how to carry out simple everyday tasks
- confusion and disorientation
- problems with memory, concentration and judgement

(Source: Not Alone 2001², and Alzheimer's Society 2003¹)

2.4 A person with dementia may withdraw from social contact and become increasingly isolated. The reasons for this include:

- feelings of shame or embarrassment at their inability to make themselves understood, carry out conversations and remember who people are
- people with dementia may be unable to converse in situations where there are a number of people talking at once or the television or radio is on
- protection of themselves or others from embarrassment due to diminishing control over their behaviour

¹ Alzheimer's Society, Facts about dementia/What is dementia?, accessed at www.alzheimers.org.uk, 23/04/2003

² McDonald A, and Curtis J, Not Alone, The Anchor Trust and the Housing Corporation, 2001

- the need for a safe or familiar environment and the fear of feeling or getting lost
- invoking hostile reactions and intolerance in others

(Source: Not Alone 2001)

It is argued that this may result in the increasing segregation of people with dementia, and social contact with other people being based only around dementia as the common characteristic. There needs to be a focus on inclusion not exclusion in society and communities.

2.5 People with dementia not only become socially isolated but also often lose both their sense of identity and the opportunity to exercise choice. '*Not Alone*' states that many people with dementia find their identity eroded by the actions, reactions and interactions of others and are denied the opportunity and support to make choices and control their own lives. For example by:

- being called by their first name, pet name or inappropriate title
- having de-personalising labels attached to them 'demented' or 'wanderer'
- being spoken to in a patronising tone of voice or mode of speech
- being ignored, dismissed or having people speak over their heads or for them
- having assumptions made about their capability and competence to make their own decisions
- having others make and decide things for them, often in their best interests but not what they would want, overprotection
- a lack of accessible information and a lack of appropriately skilled people to assist and support understanding and communication
- a limited and inflexible range of services

(Source: Not Alone 2001)

Dementia effects the quality of life of the person with dementia and also effects the carer. Carers cope with practical and social changes to their lifestyle and routines and changes in the behaviour and well being of the person with dementia.

2.6 <u>Depression</u>

Most people experience feeling low now and then, severe depression however stops a person from functioning properly, affecting work, relationships and basics such as appetite and sleep. There are several different types of depression, for example, simple depression, manic depression, seasonal affective disorder and post-natal depression. Symptoms include persistent feelings of unhappiness, feeling worthless, losing interest or enjoyment in life, tiredness, anxiety or agitation, loss of normal concentration or abilities, low esteem and low self confidence. It is estimated that depression affects one in four people at some point in their lives,³ and between 10 - 16% of those over 65 develop clinical depression.⁴

2.7 Depression can occur at any age. It has been highlighted that older people are more likely to suffer from depression if they are in poor health, lack social support or have long standing problems such as poor housing, poverty, disability and constant pain. The Audit Commission reported that

³ BBC – Health Conditions A-Z, www.bbc.co.uk/health, accessed on 08/09/03

⁴ Audit Commission (2000), Forget Me Not – mental health services for older people.

"Depression is the most common mental health problem in older people" (Audit Commission 2000)

2.8 Depression can also be often wrongly diagnosed as dementia as some symptoms are very similar such as apathy, mood swings, and erratic and confused behaviour. It is also argued that if people with dementia are denied the opportunity to assert themselves as valued and respected individuals they will often become depressed, withdrawn and frustrated. The reasons that affect this, namely why a person with dementia loses their identity and the opportunity to exercise choice and control their own lives are discussed above (2.5).

CHAPTER 3: NATIONAL AND LOCAL POLICY CONTEXT

3.1 <u>The National Policy Context</u>

The *Health of the Nation* strategy identified mental health care as a key area of policy, outlining the type of services that would be beneficial in local areas and how parts of the care network should be linked together.⁵ Joint working was identified as central to these services.

3.2 Mental Health for Older People has been made a priority in recent years by Government. The Government published guidance to promote *"Better Services for Vulnerable People*".⁶ This stated that health and local authorities, in partnership with NHS trusts should agree local joint investment plans (JIPs) identifying priorities and targets for the next 3 years, underlining the importance of multi agency working. The plans required inclusion of older people with mental illness and joint consideration of population need; current resources; current activity and expenditure; and agreed service outcomes.

3.3 *"Partnership in Action"* promoted arrangements to encourage closer working between health and social services.⁷ It stated services for older people with mental health needs should be built around their needs, but recognised traditional boundaries were often a significant obstacle. The consultation paper proposals focused on removing barriers in the system, allowing new operational flexibility. This included the relaxation of funding rules, to enable health and social services to pool their resources. The NHS Act 1999 permitted pooled budgets, lead commissioning and integrated provision.⁸ The ability for the NHS to transfer money in support of local authority services was increased (and vice versa). The closer working of agencies should lead to improvements in services for older people with mental health needs and their carers, avoid duplication, and encourage greater flexibility in the management and resourcing of mental health services for older people, ensuring public funds are spent appropriately.

3.4 The "*Modernising Social Services*" agenda details the need for Social Services to promote people's independence.⁹ Similarly other government initiatives, namely 'Promoting Independence' initiative and the 'Social Services Modernisation Fund' have shifted the emphasis of service provision to promoting independence. They too detail greater joint Social Services and Health initiatives to provide users with services at home. The Modernising Government White Paper (1999) set out key objectives for the overall approach public services should be taking in the future. These include organising public services around the needs of users of services rather than around providers; listening to people's concerns, reflecting their real lives, and involving them in decisions about how services should be provided.

⁵ Department of Health, A Handbook on the Mental Health of Older People, HMSO 1997, as cited in Audit Commission, Forget me Not, 2000.

⁶ Department of Health, Better services for vulnerable people: Executive letter EL (97)62,C1(97) 24, 1997

⁷ Department of Health, Partnership in Action, NHS Executive, September 1998

⁸ Department of Health, National Health Services Act 1999

⁹ Department of Health, Modernising Social Services, 1998

3.5 In 1997 the Royal Commission on the funding of long term care was established. The final report, *"With respect to old age: Long term care – rights & responsibilities"* was presented to parliament in March 1999.¹⁰ This examined the short and long term options for a sustainable system of funding long term care for older people in their own homes, residential care and in other settings. The report made two main recommendations:

- "Personal care", which includes nursing care and some social care tasks such as help with bathing, should be funded by general taxation, subject to an assessment of need; and,
- A National Care Commission should be established to take a strategic overview of long-term care and represent the interests of older people.

3.6 The "*NHS Plan*" for England (launched in July 2000) set out plans for the development of the NHS over a ten-year period. ¹¹ It outlines 'a health and care system focused on the service user, not around those delivering the services'. In order to achieve this vision the plan promotes the provision of preventive services; support for self-care; social care; primary care; intermediate care and hospital care. It envisages 50,000 more people enabled to live independently at home with additional home care and other support, 50% more people benefiting from community equipment services, and 75,000 more older people and their carers benefiting from respite care.

3.7 As part of the NHS Plan implementation, the strategy set out for the NHS in *"shifting the balance of power"* began a programme of change, which established a new structure, with 28 strategic health authorities (replacing the previous 95 health authorities) and more than 300 primary care trusts.¹²

The Care Standards Act 2000 extended the range of services that must be 3.8 registered and inspected. The National Care Standards Commission (NCSC) was established under the Care Standards Act (2000) as a non-departmental government body, to regulate a wide range of social care and voluntary health services. The commission registers, inspects and regulates care providers against national minimum standards set by the government. In applying the standards the NCSC seek evidence that the facilities, resources, policies, workforce, services and activities offered by providers lead to positive outcomes and experiences for service users. Care homes and Domiciliary Care providers (since April 2003) are required to register. On 19 April 2002 the government announced plans to establish two new independent inspectorates (Commission for Social Care Inspection CSCI and the CHAI), to strengthen the accountability of those responsible for the commissioning and delivery of health and social services. The two new inspectorates will not be fully operational before April 2004. Under the Care Standards Act 2000 it is also a requirement that providers, managers and staff of care establishments and agencies undergo criminal record checks through the Criminal Records Bureau (CRB).

¹⁰ Royal Commission on Long Term Care, With respect to old age: Long term care– rights & responsibilities, 1999

¹¹ Department of Health, The NHS Plan - A plan for investment A plan for reform, July 2000

¹² Department of Health, Shifting the balance of power, July 2001

3.9 The "*National Service Framework*" (NSF)¹³, published in March 2001 identifies mental health as an area of priority and outlines 8 standards for the care of older people, including

- ensuring older people's access to health and social care services is not affected by age discrimination
- developing integrated assessments and service provision to ensure care is person-centred, and individuals are enabled to make choices
- the provision of a wide range of Intermediate care services to sustain independence, enable rehabilitation, and prevent avoidable admissions to longterm care.

(Source: NSF 2001)

3.10 The NSF provides a framework for all agencies to improve their services and recommends that they work together to develop specialist dementia care places. The NSF aims to enable the NHS and Local authorities to

"... collaborate on the planning, resourcing and delivery of services for older people. The involvement of the independent sector in the planning of local health and social services is seen as essential for the delivery of high quality services to older people." ¹⁴

3.11 The NSF highlights the necessity of early detection and diagnosis of dementia. Central to this will be the educating of primary care teams, establishing good links between primary and secondary care, developing memory clinic services and creating services that can provide early support. Primary Care Trusts (PCTs) and SSD need to work jointly to develop services, single assessments and a whole system of integrated care.¹⁵

3.12 The "*Single Assessment Process*" for older people was introduced in the National Service Framework for older people.¹⁶ When fully implemented (by April 2004) this will ensure a person-centred approach to the assessment and care management of older people's needs and more appropriate outcomes. It will ensure that older people (including OPMHN) receive appropriate, effective and timely responses to their health and social care needs and that resources are used effectively. Duplication of assessment and related paperwork will also be reduced and improve the quality of information shared between agencies.

3.13 "*Integrated Services for Older People*" stresses that older people (and OPMHN) want services to be flexible, co-ordinated and focused on assisting them to remain independent for as long as possible.¹⁷ It states that "too often older people receive a confused, disjointed response when they need help or advice." This report promotes services that are organised around the user, places as much emphasis on services that promote independence as on care services, and development of a seamless integrated service. This approach means that older people and older

¹³ Department of Health, National Service Framework for Older People, 2001

¹⁴ Joseph Rowntree Foundation, The independent care homes sector: implications of care staff shortages on service delivery, Stephen O'Kell, 2002

¹⁵ Department of Health, Discharge from hospital getting it right for people with dementia, July 2003

¹⁶ Department of Health, The Single Assessment Process Guidance for Local Implementation, January 2002

¹⁷ Audit Commission, Integrated Services for older people – building a whole system approach in England, 2002

people with mental health needs have their whole range of needs and aspirations considered and that crises could be avoided. The report identified the steps to be taken to achieve this system of working. Stakeholders will need to work across traditional boundaries between Health, Social Care, Housing, PCT's, Councils and the independent sector. Care pathways should ensure availability of support to people with dementia and their carers throughout the patient journey, and as stated by the Department of Health (July 2003) consultation of people with dementia and their carers should be a key part of the process.¹⁸

3.14 *"Forget Me Not"* set out the Audit Commissions analysis of mental health services for older people in England and Wales.¹⁹ It focuses on services providing care to people with mental health needs over the age of 65 (including NHS trusts, health authorities and social services departments). The two main groups of those needing a service are identified as those with dementia and those with depression. The study highlighted that practices were variable in respect of resources available, how effectively the agencies worked jointly, carers opinions and how commissioners could shape provision. The report found inequity of provision for older people and their carers, who often did not receive the help they needed when they needed it. Forget me not detailed the importance of joint working in order to provide

- help and advise when problems arise
- specialist services, especially to people in their own homes
- co-ordination between agencies and professions
- a comprehensive strategy to ensure all the components are in place.

(Source: Audit Commission, Forget me Not, 2000)

3.15 The new policy focus is on providing high quality consumer led services offering informed choices, which deliver better outcomes. The cross cutting theme of the promotion of greater independence runs across almost every area of health and social care. This change of emphasis has required a change in culture, attitudes, services, structures, systems and ways of working across agencies. Current policy encourages people to remain in their own homes, with the support of social services, friends and family if necessary. This also fits with the reported preferences of older people to live at home for as long as possible and feasible.²⁰

3.16 In addition the Carers' Recognition and Service Act 1995 gives carers the right to an independent assessment of their need, if the cared for has a right to a community care assessment.²¹

3.17 Local Policy Context

"Active Care – A new look at Social Care in Kent" was presented to the Social Services Committee in September 2000 and sets out the general direction of Kent County Council and a number of commitments and targets for social care in Kent over a ten-year period.²² The direction is consistent with KCC's "Opportunities for

¹⁸ Department of Health, Discharge from hospital getting it right for people with dementia, July 2003

¹⁹ Audit Commission, Forget Me Not – mental health services for older people, 2000

²⁰ DTLR, Quality and choice for older people's housing, A Strategic Framework, 2001

²¹ Department of Health, The Carers' Recognition and Service Act, 1995

²² Kent County Council, Active Care – a new look at social care in Kent, September 2000

Kent – the vision" and underpins the public service agreements. The envisaged changes include

- every older person having the support to stay in their own home or community if that is what they desire,
- services being integrated, co-ordinated and seamless at the point of delivery,
- people caring for others on an informal basis are supported in doing so,
- users and carers playing an active role in monitoring services provided and the development of future services.

(Source: KCC, Active Care – a new look at social care in Kent, September 2000)

3.18 "The Kent Charter for Long Term Care" aims to provide co-ordinated support from Housing, Health and Social Services to enable older people (amongst others) to live independently and family or friends to continue to offer support.²³ The Charter sets out the values on which people can expect local housing, health and social services to be based. The Kent Charter values include achieving and sustaining maximum possible independence; to work in partnership; and involving clients and carers in decisions.

3.19 *"Kent – The Next Four Years"* outlines Kent County Council's priorities and targets for the next four years to 2005.²⁴ In regards to older people and the provision of residential care and alternative modes of care it sets challenging targets to

- work with the Government and Kent partners to support independence, targeting dependency, ... re-investing savings into preventative services.
- support those who care for others, expanding respite care and support by 20%.
- promote housing to enable frail older people to live at home; ensure an additional 1,000 well designed units of sheltered housing are provided across Kent.
- double the number of recuperative care beds available for older people and prevent unnecessary admissions to residential care.
- develop home care services for people in their own homes so that 20% more people would benefit from intensive home care, and who want to live at home, can do so.
- increase the range of care and nursing support services in communities and reduce the number of emergency admissions of older people to hospital by 10%.
- locate KCC care staff at any doctor's practice where this helps patient care and is useful to the NHS

(Source: KCC, Next Four Years 2002)

3.20 *"Vision for Kent"* is the community strategy document and focuses on improving the economic, environmental and social wellbeing of the county of Kent over the next 20 years.²⁵ This provides a framework for all Public Agencies in Kent to work together. It reflects Kent's priorities as well as those for other agencies including the Health Authority. One of the key themes is 'Modern Social and Health Care Services'.

²³ Kent County Council, Better Care – Higher Standards: A Kent Charter for Long Term Care, August 2001

²⁴ Kent County Council, The Next Four Years, 2002

²⁵ Kent County Council, Vision for Kent, 2001

3.21 In 2001 the Government introduced the concept of Public Service Agreements (PSA) for local authorities, encouraging commitment to achieving targets agreed with local people and partners. If targets are achieved, as an incentive to better performance locally, central government return a proportion of the reductions in the cost of social dependency as a financial reward for reinvestment in preventative work by the public service providers. The "Kent Agreement 2001-2004 (PSA)" is a group of targets agreed with government that contributes to the aim of 'Reducing dependency – increasing employment and fulfilment'.²⁶ Two of Kent County Council's Public Service Agreements relate to older people. The two targets are:

- to reduce delays in moving people over 75 from hospital
- to reduce numbers of people over 65 moving into residential and nursing care.

To achieve the targets a broad range of efficient and professional services to support care at home are essential.

3.22 "Active Care – Active Lives: A new look at Social Care in Kent" has been published as a guide to all those who contribute to the care of vulnerable people in Kent.²⁷ There is a renewed emphasis on proactive and preventative care and conveys continuous change and evolution with a broad vision of empowering people and helping them to be independent. This begins to turn the vision of 'Active Care' in 2000 into reality. The original commitments remain unchanged but reflect upon changes that have influenced the emerging strategy, including

- national developments in setting service standards, joint working and policy
- local aspirations as detailed in Kent the Next Four Years, the Vision for Kent, the Kent Public Service Agreements and Supporting Independence programme.

3.23 The "*KCC Annual Plan 2003*" combines KCC's strategic objectives, priorities for improvement in 2003/04 and outcomes 2002/03.²⁸ It outlines KCC's commitment to deliver the Vision for Kent; the Next Four Years; the Kent Agreement and the Annual Plan. The Annual Plan is important as it sets out the achievements, priorities and plans to improve services. One of the priorities is to implement legislative change and national guidance in Adult services, including the National Service Framework for Older People; the Single Assessment Process; 'Fines' for delayed discharges and results of the National Care Standard Commission inspections. Implementing the changes required will result in improved services.

3.24 The "Adult Services Plan 2003/04" describes the purpose of Adult Services to help older people (and people with learning/physical disabilities) to live as independently as possible in their own communities.²⁹ The Plan incorporates services commissioned and delivered to older people, also covering the county-wide direct services (e.g. the Older People's Direct Services Unit (Linked Service Centres) and Kent Home Care Services). The plan provides an overview of budget, policy and service provision. Activities and targets are contained in the District Business plans (April 2003). The directorate are committed to the principles and delivery of Active

²⁶ Kent County Council, KCC Annual Plan, June 2003

²⁷ Kent County Council, Active Care – Active Lives: A new look at Social Care in Kent, March 2003

²⁸ Kent County Council, KCC Annual Plan, June 2003

²⁹ Kent County Council, Adult Services Plan: Budget and Business Plan 2003/04, 2003

Care – Active Lives, Next Four Year targets and the PSA agreements relating to the promotion of independence for older people through additional recuperative and outreach facilities and innovative social care, health and supported housing programmes.

3.25 The "Social Care Eligibility – Standardising Assessed Needs to Indicate Entitlement to Services" sets the criteria for those eligible for help from Kent Social Services Directorate (SSD). An assessment of need is carried out and compared against 'service entitlements' to identify the band of service options to which a person may be entitled to. A person must be assessed as having a 'Moderate' level of need for temporary or low level domiciliary care, and a 'High' or 'Very High' level of need in order to be entitled to a domiciliary care package. A current care package cannot be cut back without a reassessment regardless of any financial crises a local authority may have.

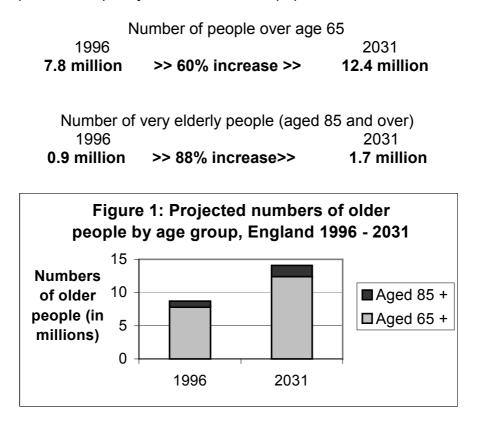
3.26 The SSD recommends the service(s) that they consider to best suit the individual assessed as needing care e.g. residential/nursing home care, domiciliary care. Clients do however have the right to challenge an outcome and a right to choose to remain in their own home. Although client and carer views are taken into account, this needs to be balanced with available resources and capacity. The level of care needed may be beyond the available resources of SSD or the capacity available, for example if a client requires 24hour care but SSD are unable to find carers to cover this. There may also be increased issues of risk if a person remains at home if this is not thought to be the most appropriate setting to meet the assessed needs. Clients' wishes are therefore met as far as possible.

3.27 From the various policies highlighted above both at a national and local level, it is clear that joint working and increasing the independence of older people will shape the provision of successful community care services. The greater emphasis placed on supporting older people in their own homes or community; more joint initiatives between Social Services and the NHS; with increased resource allocation linked to meeting targets, the need for professional services in support of care at home and in alternative settings has never been higher.

CHAPTER 4: DEMOGRAPHICS

4.1 <u>The National Picture:</u>

The demand for Dementia Care is expected to rise in the future placing a greater significance on the need for a well co-ordinated and good quality service. Demographic studies predict sharp increases in the numbers of older persons who will require specialist long term care in the future. PSSRU have illustrated the likely steep rise in demand for social care resulting from population changes over the next 30 years.³⁰ The number of very elderly people (aged 85 and over) is expected to rise even more rapidly, with reported changes of the number of individuals aged 85 years and over expected to triple by 2056. This rise in population is illustrated below.



4.2 PSSRU state that the Government's Actuary's Department (GAD) estimates the number of people in England aged 65 and over will rise by 4.6 million from 1996 to 2031, an increase of 60 per cent. The number of very elderly people (aged 85 and over) will rise even more rapidly, by 88 per cent, from 0.9 million in 1996 to 1.7 million in 2031. These statistics exacerbate the care situation for the future. There is an increasing ageing population and the number of potential carers (be they professional or informal) is decreasing.

4.3 An ageing society creates new challenges. PSSRU state these projections mean long term care expenditure will need to rise by 150% in real terms over the next 30 years to meet demand. Dependency is also a crucial factor in considering need as this rather than age influences the need for care. The DOH estimates that

³⁰ PSSRU, Demand for Long term care for older people in England to 2031, LSE and U of Kent 2001

men's average life expectancy includes eight years of poor health, for women this is nearly 11 years.³¹ This has implications for older people and decisions on living and care arrangements. This increase in population and rise in demand for care is likely to lead to a boom in the independent care sector.³² Initial analyses from the 2002 Census show that nationally,³³

• the number of people aged over 85 years has increased, now over 1.1 million

• people aged over 60 years (21%) form a larger part of the population than children under 16 (20 %).

4.4 The financial pressures due to projected demographic changes affect both the health service and social care. HMT (2002) highlighted the pressures on social care, forecasting

'spending on the elderly and on adults with mental health problems and physical and learning disabilities rising from £6.4 billion in 2002/3 to between £10.0 - £11.0 billion in 2022/23 ... demographic change and, in particular, the ageing of the population is a more important cost pressure for social care than for health care...These figures do not include estimates of any additional increase in the level of resources required to deliver high quality social care or more imaginative planning of the whole of social care. The figures quoted are therefore under estimates of the additional resources that will be required.'

(Source: HMT 2002)³⁴

4.5 <u>Demographic Trends and Prevalence of Dementia</u>

Demographic studies show a clear relationship between age and the prevalence of dementia.³⁵ It is argued that improvement in life expectancy in the UK is likely to increase the number of cases of dementia in the elderly population. Kent, with a high proportion of older people, especially in East Kent, will probably see a significant rise in the number of cases of dementia. The Kent population aged 65 and over is expected to increase by 10.5% by 2011.

4.6 The expected number of cases of dementia (or prevalence) increases with age, especially after the age of 80. One in five people over 80 have dementia. Predicted prevalence rates differ across surveys, due to variations in research methodology. However there is significant agreement that prevalence of dementia rises sharply with age. Table 1, Table 2 and Figure 2 illustrate the link between dementia and age, showing 25% of those over 85 years of age have dementia and that over the age of 65 dementia is more common in women.

³¹ Department of Health, The governments response to the Royal commission on Long Term care, July 2000

³² Joseph Rowntree Foundation, The independent care homes sector: implications of care staff shortages on service delivery, Stephen O'Kell, Jan 2002

³³ Office for National statistics, Census 2001: First results: total population by age and gender, 2002

³⁴ Wanless D, Securing our future Health: Taking a long term view, HM Treasury 2002

³⁵ Alzheimer's Disease International, The prevalence of dementia, April 1999

| Age | 30- 59 | 60- 64 | 65-69 | 70-74 | 75-79 | 80- 84 | 85-89 | 90+ |
|--------|--------|--------|-------|-------|-------|--------|-------|--------|
| Male | 1.6 | 15.8 | 21.7 | 46.1 | 50.4 | 120.9 | 184.5 | 320.0 |
| Female | 0.9 | 4.7 | 11.0 | 38.6 | 66.7 | 135.0 | 227.6 | 328.2 |
| | | | (0 | | | | | 100436 |

Table 1: Dementia prevalence rates by age-sex per 1000 population.

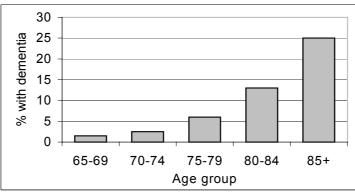
(Source: Hofman, A. Rocca, W.A. et. Al, 1991)³⁶

Table 2. Percentage of dementia cases in people over 65 years by age group.

| ,,, | 1 | 1 /* | | | | | |
|-----|-------|-------|-------|-------|--------|--------|--------|
| % | 1.0 % | 1.4 % | 4.1 % | 5.7 % | 13.0 % | 21.6 % | 32.6 % |
| Age | 60-64 | 65-69 | 70-74 | 75-79 | 80-84 | 85-89 | 90+ |

(Source: Hofman, A. Rocca, W.A. et. Al, 1991)

Figure 2: Estimated prevalence of dementia



(Source: Forget Me Not, Audit Commission 2000)

4.7 With the rate of dementia increasing the problem of meeting future demands on services is critical. It is estimated that 11% of those with dementia need 'long interval care', nearly 50% 'short interval care' and 34% 'critical interval care'. (This is defined in Appendix 2).³⁷ The demographic changes and impact of early onset dementia, although not the focus of this report should also not be overlooked as will increase demand for dementia services as a whole, with studies finding 67.2 cases of early onset dementia per 100,000, an estimated16,737 cases throughout the UK.³⁸

4.8 Future demographic trends forecast an increase in the number of people over 85 years by 2031. On a national level this is likely to result in a dramatic increase in the number of cases of dementia. Kent's demographic trends suggest a significant increase in the demand for dementia care services in the early part of the 21st century. A rise in the number of cases of dementia on this scale would place considerable demands on local health and social care services. Long-term care services for older people will need to expand to keep pace with demographic

³⁶ Hofman A, Rocca WA, Breteler MMB, The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings', International Journal of Epidemiology 20, 736-748, 1991, as cited in www.alz.org/dementia / Dementia statistics

³⁷Audit Commission, Forget Me Not – mental health services for older people, 2000

³⁸ Harvey R, 1998, Young Onset Dementia: Epidemiology, clinical symptons, family burden, support and outcome. NHS Executive (North Thames), as cited in Alzheimer's Society, Younger People with dementia, accessed at www.alzheimer's.org.uk

pressures. The Personal Social Services Research Unit estimates that 'the number of home care hours would need to increase by around 48 percent between 1996 and 2031 (PSSRU, 2001). Innovative strategies need to be developed to aid traditional health and social care interventions.

4.9 <u>Prevalence of Depression</u>

Many studies have looked at the prevalence of depression. The expected number of older people with major depression is

"... similar to that seen in working age adults, but the prevalence of significant depression is 15% in the general elderly population, with particular high risk groups such as those receiving home care (26%) and those in residential care (50%). Duration of depression is longer and relapses more common in later life." ³⁹

It is often assumed that depression is an inevitable part of ageing. Studies have shown that although effective treatments are available elderly people often see suicide as the only option and the risk of suicide increases with age. Depression is also reportedly more common in the years after retirement. Illness can increase the risk of depression and also some drugs can cause, aggravate or trigger depression, contributing to depression being more common in elderly people. For example depression often occurs after a stroke or using beta-blockers, and effective treatment can be critical for a return to normal abilities.⁴⁰ Depression is also common in residential care. Research has found that 40-50% of people in residential care were clinically depressed and that one quarter of those receiving home care were depressed.^{39, 41}

4.10 Research has shown that appropriate treatment is essential and in the majority of cases depression can be successfully treated. This includes using anti-depressant drugs to restore balance, and social support and psychotherapy to tackle many of the triggers of depression. Macnair states that "despite this the World Health Organisation estimate that by 2020, depression will be the second largest cause of death and disability in the world". Macnair argues that tackling the issue of social isolation is key when treating depression in older people and being part of a family or community is beneficial compared to living in care, which doubles the risk of depression.

4.11 <u>Prevalence of dementia and depression among elderly people in Black and ethnic minorities</u>

Major studies show that elderly people from ethnic minorities may be at particular risk from dementia and depression.⁴² Despite this, it is reported that few such people have received psychogeriatric services (Brownlie 1991, Manthorpe and Hettiaratchy

³⁹ London Health Observatory, Mental Health :Elderly, www.1ho.org.uk, accessed on 08/09/03

⁴⁰ Macnair Dr Trisha, Elderly People and depression, www.bbc.co.uk/health/features, accessed 08/09/03

⁴¹ Audit Commission, Forget Me Not – mental health services for older people, 2000

⁴² McCracken, Boneham, Copeland, Williams, Wilson, Scott, McKibben and Cleave, prevalence of dementia and depression among elderly people in Black and ethnic minorities, British Journal of Psychiatry (1997) 171. 269-273

1993).⁴³ This is partly attributed to lack of routes into formal services and symptoms being unrecognised due to difficulties of communication or cultural differences. Major studies have also shown that some ethnic groups are more likely to see depression as a weakness of character or normal ageing.

⁴³ Brownlie 1991, Manthorpe and Hettiaratchy 1993, as cited in McCracken, Boneham, Copeland, Williams, Wilson, Scott, McKibben and Cleave, Prevalence of dementia and depression among elderly people in Black and ethnic minorities, British Journal of Psychiatry (1997) 171. 269-273

CHAPTER 5: RESIDENTIAL CARE HOMES

5.1 As detailed in Chapter 3 recent policy has focused on independence and keeping older people at home for as long as possible. Despite this there are times when this is no longer a feasible option. It is likely that there will always be a need for some care home provision, particularly for the most dependent.⁴⁴ In the future this needs to develop to be seen as positive and quality option. The factors that contribute to admission to a residential care home are discussed in 5.3.

5.2 Residential care home services, including homes for OPMHN are provided in a diverse market. The *Caring for people* ⁴⁵ reforms indicated the need to promote the development of a flourishing independent sector alongside good quality public services. This has been achieved to a considerable extent for residential care services. Since the 1980's the growth of the independent sector, and a proliferation of small businesses have provided the majority of residential care beds. Third sector and local authority provision have accounted for a declining market share as the independent market expanded.⁴⁶ The ability to offer choice and quality to OPMHN depends on providing a stable and competitive care homes sector. The independent care sector is currently going through a period of change, influenced by legislation on how care is commissioned, provided and inspected.

5.3 <u>Reasons for admission to residential care homes</u>

Dependency on entry into residential care is higher (and people are now living longer). Major factors associated with admission into long term residential care are

- Fear and doubt about living at home
- Inadequate living arrangements
- Limited user choice
- Increased impairment and disability
- Lack of community services
- Carers' stress and lack of support to care
- Poor or ineffective assessment
- Lack of service flexibility
- Professional and organisational concerns and interests

(Source: PSSRU, Implementing Caring for People, DOH July 1994)

Alongside these there are further reasons that influence the entry of OPMHN into residential care. Analysis showed that the key reasons of admission for OPMHN to residential care in West Kent were disorientation at home, anxiety of being alone, wandering (at day or night), safety at risk, need for constant supervision, reduced social interaction (often becoming based around care workers) and for some severe depression. There is also a concern that the G.P contracts may lead to an increased use of locums who will not know individuals and result in an increase of inappropriate

⁴⁴ Robin Darton and Ann Netton, Discussion paper 1862: What potential is there for replacing residential care provision with other assisted living options? PSSRU March 2003

⁴⁵ Department of Health, Caring for People Reforms 1993

⁴⁶ Kendall J, The third sector and social care for older people in England: Towards an explanation of its contrasting contributions in residential care, domiciliary care and day care. Civic society working paper 8, 2000

referrals to residential care. There is a need to strike a balance between the protection of older people and the quality of life gains that come from taking some risks.

5.4 <u>Future demand for residential care</u>

Residential care homes and nursing homes looking after older people provide a home for approximately 5% of older people.⁴⁷ PSSRU estimated that there is one care home place for approximately every 10 people aged over 75.⁴⁸ The majority of these places are in independent homes but three-quarters are state supported, mostly by local authorities. The PSSRU care home report estimate that one man in six, and one women in three will enter a care home for older people at some point in their care, and that the probability increases with age, as does the prevalence of dementia. At the Long term care 2002 Conference it was reported that:

"Care homes continue to close at an alarming rate. The care home sector has lost ... nearly 10% of its original capacity. Whether or not this trend will continue is debatable but what of the future? The number of people over the age of 85 years will increase from 1.1 million to 3.3 million over the next fifty years. A survey conducted by the London School of economics on behalf of the Department of Health concludes that residential and nursing care places will need to increase by 7 to 8% by 2010, even with a similar increase in home care hours."

(Source: Richardson, 2002)⁴⁹

5.5 The Department of Health have projected that if patterns of care or dependency rates remain constant, "the numbers of older people in residential care homes (and nursing homes) will rise between 2000 and 2020 by 23%. ... A shift in the balance of care from residential to home care reduces the projected increase in demand."⁵⁰ Within care homes the proportion of residents who have dementia is rising.⁵¹ The growing numbers of people with dementia have led to an increase in demand for specialist care homes providing high guality care for high dependency clients. Kent Community Housing Trust (KCHT), established to provide residential, respite and day services to OPMHN and the physically frail reported that they have seen a rise in demand for specialist care beds. They estimated that in 1992 about one-quarter of their residents had special dementia needs, today this is almost threeguarters of residents. Due to the rising numbers of people with dementia and the demographic pressures provider organisations may increasingly need to consider setting up specialist dementia care homes or units within homes. (This is discussed in greater detail in 5.35 and 5.36).

⁴⁷ Alzheimer's Society, Lets set a fair rate for care, Winter 2001/Spring 2002

⁴⁸ Bebbington A, Darton R, Netten A, Care Homes for Older People: Volume 2 Admissions, needs and outcomes, PSSRU 2001

⁴⁹ Richardson Frank, Latest Developments in the Long Term Care Market, Annual LTC for older people conference, March 2002

⁵⁰ Department of Health, The residential care and nursing home sector for older people: an analysis of past trends, current and future demand, August 2002

⁵¹ Joseph Rowntree foundation, Put yourself in my place – designing and managing care homes for people with dementia, Cantley and Wilson, 2002

5.6 In recent years government policy has given increasing priority to the independence of older people, enabling them to remain at home for as long as feasible. This shift does not mean that residential care is no longer needed. It was a common opinion of both witnesses and Members that there will always be a need for residential care, but that the future might see a more focused service for particular client groups, such as OPMHN and a reducing market share as alternatives develop. Residential care in the future needs to be seen as a positive and quality option. Providers stated that the role of residential care is changing and will continue to change and evolve over time. KCHT proposed that this could include a larger part to be played by private providers in the provision of rehabilitative care across the county.

5.7 Fair price for care and provider viability

The increase in demand for specialist care homes is set amidst a potential '*Care Home Crisis*'.⁵² This study highlighted the increasing numbers of home closures; rising fees; and a shortage of places leading to difficulties for many older people finding suitable or affordable room in a residential care home. The National Care Homes Association (NCHA) believe there is a crisis in care due to the:

- underfunding of care over the last 15 years
- difficulties in recruitment and retention of staff
- national standards undermining the confidence of care homes and the lending banks,(cautious of an uncertain market with increasing closures)

(Source: NCHA)⁵³

5.8 This is a view supported by the Kent Care Homes Association (KCHA). Independent providers, including the NCHA, KCHA and KCHT report that the sector is in difficulty and that they are unable to provide quality care at the fee levels given or have a good level of return. It is argued that fees paid by local authorities to providers have not mirrored the increasing costs born by providers, leading to a funding gap.⁵⁴ Some of these additional pressures are discussed below.

5.9 The social care market is influenced by many factors that increase pressure on the residential care home sector. These include the increasing emphasis on community care and alternative care support; workforce issues; G.P contracts; Community Nurse support; and financial implications of costs for insurance, criminal record bureau checks, registration and changes to the National Minimum wage. The rising costs amount to approximately an extra 30% in running costs for residential homes in 2003 compared to 2002.⁵⁵ For Kent residential care homes this includes:

- insurance costs have increased by 300% (for some care homes) over 1 year
- criminal record bureau are due to increase charges from £12 to £29 per person
- increase in inspection/registration fees by up to 20% in 2003
- need for training to meet NCSC requirements

⁵² Which? Report, Care Home Crisis, February 2003

⁵³ NCHA, NCHA responses to government - Care in Crisis? A report by the NCHA, 6 February 2003

⁵⁴ SPAIN, The underfunding of social care and its consequences for older people, November 2001

⁵⁵ Care and Health Magazine, Conversation with Nadra Ahmed, Issue 34 April23 – May 6 2003, 2003

These are significant pressures on Kent care homes given the numbers of staff involved and home turnover levels, at a time when there is increasing demand for specialist provision and reducing numbers of care homes.

5.10 Increasing numbers of Kent providers need to keep occupancy levels high to remain viable. Local Authorities, including Kent set maximum fee amounts that they normally expect to pay for the cost of residential care. Providers have stated this is too low to remain viable and that often self-funders are subsidising shortfalls in local authority fees. (Fee levels are discussed below in 5.12 and 5.13). Reduced viability and the low rate of return have contributed to the closure of many care homes.⁵⁶ This trend is expected to continue, when there is already an identified shortage of dementia care beds in many parts of the country.⁵⁷ Due to the low fees on offer and reduced viability, many care homes have opted to not accept local authority placements. Historically in Kent a small number of homes have opted not to contract with Kent. This contract is currently being re-let and first signs are that more homes may choose to not contract with Kent. Laing and Buisson have stated the key to new investment is to offer the independent sector 'reasonable fee rates' to support the 70% of care homes funded wholly or partly by councils.⁵⁸ To reinforce this, Richardson argues that no one will invest in building new homes on any scale whilst state funded fees remain so low.59

5.11 There are reported benefits in having small-scale units (8-15 residents), but corporate providers achieve competitive advantage through economies of scale, finding for economic reasons it necessary to have group sizes of 15 with overall home sizes of over 45 residents.⁶⁰ Both large and small care home providers can deliver high quality care, though they may offer different experiences for both living and working. It is unclear how the changing trend towards larger providers will affect these experiences. The Kent Care Homes Association reported to the Committee that this emerging trend can be seen across Kent, and that the 'smaller market' needs support. KCHT informed the committee that in the current situation the minimum viable size was not less than 40 residents, and that most homes had enquiry lists for availability. The National Care Standards Commission (West Kent Area Office) confirmed this trend, stating that after the initial scare there seems to be a resurgence of providers wanting to enter the Kent market, mostly large providers as smaller homes are less viable.

5.12 Fee levels

Providers and campaigners, both in Kent and nationally consistently state that fee levels are too low to ensure continued delivery of high quality care, improved standards and an adequate return to owners and operators. National figures for residential care are as low as £225 per week, less than the cost of staying in modest

⁵⁶ PSSRU, The residential care and nursing home sector for older people: An analysis of past trends, current and future demand, August 2002

⁵⁷ Joseph Rowntree Foundation, The independent care homes sector: implications of care staff shortages on service delivery, Stephen O'Kell, Jan 2002

⁵⁸ The MJ, Fines threat issued over care homes, 14 august 2003

⁵⁹ Richardson Frank, Latest Developments in the Long Term Care Market, Annual LTC for older people conference, March 2002

⁶⁰ Joseph Rowntree Foundation, Put yourself in my place – designing and managing care homes for people with dementia, Cantley and Wilson, March 2002

bed and breakfast. The Laing cost model analysis concludes that fees paid by councils are between £75 and £85 a week below the reasonable costs of running an efficient and good quality home, based on a 'standard cost model' with relatively high rates of return.⁶¹ The average fee for a residential place would increase from £268 to £353 per week, not including any enhanced payments for specialist care. Local authorities, including Kent assert that they are inadequately funded to meet the rising costs. The JRF report also acknowledges this and that councils could not afford an immediate increase on this scale. An increase in fees is also only likely to sustain capacity rather than directly increase it in the short term. This would be an increase of 27% on Kent fee levels for Districts in band one set at a basic band price of £280 per week (for new placements since April 2003). In comparison the National Care Homes Association have proposed a £50 per week increase.⁶²

In 1999 two key drivers led to beds being specifically contracted for OPMHN in 5.13 Kent. Providers caring for OPMHN identified the need for different support mechanisms to be in place and monitored. There was also an identified need for information in order that care managers knew which homes were suitable to meet the needs of OPMHN. The Joint Review (2001) stated that Kent SSD had recognised the need to increase differentials in pricing to encourage more provision for older people with mental health needs. Kent SSD agreed targeted price increases of 6-14% compared to the standard 3-4.5% for non-specialist homes. Higher band prices are set for older people with dementia; these are £339 and £370.80. At the time of this review the contracts were going through the re-let process. A further level of care has been introduced into the current contract re-let. The 'Enhanced Care Premium' (ECP), introduced in July 2003 will attract a premium payment from SSD and recognises the increasing levels of dependency, responsibility and care. The ECP increases the band prices for the most highly dependent older people to £310 and £325 respectively, recognising the increasing dependency levels of clients and the increased levels of responsibility and care resources needed.

5.14 Capacity and provision of specialist residential care beds

Kent County Council provides residential care home services through contracts with the independent sector and in-house facilities. The contracted capacity figures indicate the number of beds providers are willing to consider referrals from Kent for. The Kent SSD contracts account for approximately 42% of the contracted capacity and 37% of the total residential care market within Kent (including self-funders and other local authorities). For EMI Beds this is 59% of contracted capacity and 52% of total market capacity. It is difficult to gain precise figures on the balance in any home between local authority (Kent), other local authorities and self-funders. However the issue is whether the contracted capacity is accessible to KCC in preference to other purchasers. As highlighted in the "*Joint Review*"⁶³ Kent SSD has developed a very sophisticated contracting strategy for securing residential care from the independent sector, that re-let contracts on a four year cycle. The review stated that this had enabled the authority to "maintain a strong downward pressure on prices, but this had been relaxed to counter the accelerating closures of residential care homes".

⁶¹ Joseph Rowntree Foundation, Press release - Care homes for older people 'underfunded by over £1 billion a year'. Calculating a fair price for care: A toolkit for residential and nursing care costs, William Laing, 2002

⁶² National Care Homes Association, NCHA responses to government - Care in Crisis? 6 February 2003

⁶³ Social Services Inspectorate and Audit Commission, Joint Review of Kent Social services, October 2001

These contracts are now open ended to reduce transactions for providers and the authority. The Select Committee also heard from providers that despite differences during commissioning there was a strong commitment within SSD to build partnerships and that the commissioning process was clear and fair.

5.15 In similarity to national trends there has been a continued reduction in the number of residential care beds in Kent. This is due to both the numerous home closures within Kent and also homes opting to no longer trade with KCC. KCHT also reaffirmed that low rates of return and the dramatic increases of land prices in SE England have contributed to this, with the option to sell care homes to developers becoming quite attractive as more money can be made. If spaces are limited and choice restricted, OPMHN will have difficulties in exercising any real choice.

5.16 In 1999 15,000 residential places were lost nationally (about 3.7% of capacity). In 2001 there was a net loss of 5 -10,000 beds, about 1-2% of care home capacity.⁶⁴ Although nationally home closures are no longer accelerating and have apparently stabilised, across the UK between Jan 02 and April 03, a total of 13,400 places were lost.⁶⁵ The total numbers of lost care places are substantial and in addition levels of new registrations continue to be low.

5.17 Kent lost 20% of the contracted residential care home beds from April 1999 to 31 Dec 2002. On average the Kent EMI contracted bed losses for the same period were 8% (East Kent 7%, Mid Kent 11% and West Kent 5%). Overall there has however been an increase in the provision of EMI beds as a direct result of the SSD policy to specify and contract services separately and more providers entering the market than leaving it. Levels of contracted capacity indicate the highest shortage of provision in Swale for OPMHN. In contrast KCHA identified gaps in OPMHN provision in Tonbridge, Tunbridge Wells, Sevenoaks and Dartford, partly due to London Borough placements who pay on average £450, attracting Kent based providers away from taking Kent placements. This illustrates that although contracted capacity is good, actual beds may not be available. In relation to residential beds in the Older People Direct Services Unit (OPDSU), two thirds of their business, it was reported that occupancy rates between February and July 2003 had a void rate of 4% (about 20 beds). This was extremely good as normally expected 90% occupancy. The OPDSU are increasingly focused on providing care to more complex cases and higher dependency levels and also providing a greater proportion of their business as respite and day care.

5.18 Under the Local government Act 2000, the building care capacity grant £300 million has been allocated as 'cash for change' to local authorities to help build capacity in care provision across the board with agreement to place older people in care homes or give them alternative forms of support.⁶⁶ Kent County Council allocations for 2001-2002 were £2,115,976 and 2002-2003 allocations were set at £4,447,274. There was some concern around the quality of care provided for those with mental health needs. Part of the grant is being used to fund a Dementia Support worker to support care homes and improve quality of life, assisting with care plans activities and nutrition. Kent County Council have also received £1.216 million in

⁶⁴ Annual Long Term Care for Older People Conference – A fair price for Care, William Laing 2002

⁶⁵ The MJ, Fines threat issued over care homes, 14 August 2003

⁶⁶ Department of Health, Press release 9.10.2001

reimbursement funds from the Government for 2003/2004 and this is expected to rise to c.£2.4 million for each of the next two years. Kent SSD and the NHS have agreed locally to invest this money in preventative services and those designed to expedite discharge from hospital. These services aim to increase the market capacity to enable 'step down beds' and interim placements to be available, strengthen intermediate care services and facilitate discharge arrangements from hospital. More than 40 schemes have been agreed in Kent. Some of these schemes are specifically aimed at OPMHN, for example, in South West Kent four schemes are designed to enhance the OPMHN Emergency Response service (including day care).

5.19 The Committee heard evidence that there were limited specialist places for OPMHN and shortages within some areas of Kent and that carers often had difficulties in finding a place for an older person with mental health needs. Carers stated that there was pressure to accept a place somewhere they felt was not suitable due to care standards, environment or geographic location. Residents often have to enter a care home away from their home area, severing local community ties and familiarity, even though overall numbers of OPMHN beds have increased. Finding OPMHN beds also needed to be timely as when carers reached the point where they could no longer cope they needed a quick response. Specialist provision at current levels is unlikely to meet the future demographic pressures and dementia prevalence for OPMHN, however a combination of care arrangements that include specialist care homes will be better able to meet future demand.

Recommendation: SSD need to assess and quantify trends, costs and demand for residential care for OPMHN over the next 10 years.

Recommendation: SSD should develop a plan to identify the trends and how demand for residential care for OPMHN can be met over the next 10 years and how provision can be encouraged where appropriate.

5.20 The 'exercising of choice' is for a home that is deemed suitable to meet the needs of the client. Lack of availability, restricts choice before budget and meeting individual needs are even considered. Fuelled by the falling numbers of care homes Mr Laing (of Laing and Buisson) said

"without new investment in care home capacity consumer choice is threatened. The government will find it harder to achieve delayed discharge targets and local authorities will have to work harder to avoid fines." ⁶⁷

5.21 As discussed earlier, choices of homes are also limited by the amount that individuals or the local authority can afford to pay. Over 70% of older people in residential care are funded wholly or partly by local authorities at a level homes argue reduces their viability. The Select Committee heard from informal carers, that in order to exercise choice to enter a particular home older people would often need to enter a waiting list. In this particular instance the 'cared for' remained in a NHS hospital "taking up valuable beds and increasing length of waits". The Committee were told that the labelling of loved ones as 'bed-blockers' caused added distress at an already difficult time when trying to find the best solution and appropriate and available

⁶⁷ The MJ, Fines threat issued over care homes, 14 August 2003

residential care. One carer also expressed concern that the lack of availability and choice restricted opportunities to relocate (an option not favoured by SSD) if the client/carer found the home unsatisfactorily met their expectations, placing clients/carers in the hands of providers with fear of victimisation if complaints were made. Given the limited choice available for OPMHN this is of concern. Members were particularly concerned about this issue and brought it to the attention of the Social Services Directorate directly.

5.22 <u>Recruitment and retention</u>

"Future Imperfect" ⁶⁸, the Kings Fund Inquiry, detailed many of the problems currently affecting social services staffing, including lack of training, hurried service delivery and recruitment problems due to poor pay and conditions. Similarly a recent study stated that *"the independent care homes sector"* ⁶⁹ is no longer an attractive career option, a view supported by KCHT, the Kent Care Homes Association and the NCHA. There are better jobs offering more money available in the commercial sector (especially for unsociable hours) e.g. stacking supermarket shelves, leaving the care home sector unable to compete for staff. The study found that care homes in rural areas usually experience more recruitment problems than those do based in towns.

5.23 KCHT said there was a 'timebomb' in care staff recruitment ahead unless people were encouraged to work and make a career in care, and to achieve this 'care jobs' needed to be within a career structure and seen as worthwhile and satisfying. KCHT argued that this needed to be underpinned by salaries for staff parallel to those in the NHS, government backed support of training, image and career path promotion, and a grounding in care prior to entry to the NHS. A large cultural change is needed that incorporates better training and career progression, which however is not welcomed by the current workforce in its entirety. KCHT confirmed that the possibility of higher salaries attracted many staff to work elsewhere, and that it was difficult to recruit staff with the right motivation and capacity to care, especially for OPMHN. If there is to be a reliable service for the increasingly frail and OPMHN there needs to be an increase in the level of skills and awareness of dementia and depression, and the availability of support for staff. One of the keys to retaining staff is keeping levels of motivation high. Major care staff motivators identified are:

- Employee friendly manager/owner who values and respects care staff
- Happy place to work with emphasis on good communications and teamwork
- Homes that assist staff to take up education and training opportunities
 (Source: IPE_Stephen O'Kell_Japuary 20)

(Source: JRF, Stephen O'Kell, January 2002.)

5.24 Care staff qualifications and training

Financial pressures have meant low salaries for care staff, which in turn affects the calibre of care staff attracted. The National Care Standards Commission also require that care staff have more training, which should improve standards of care but is likely to further increase costs to providers. It has been emphasised that training is a particular concern. JRF findings showed that few homes had 'reached the target of

⁶⁸ Kings Fund, Future Imperfect – the care and support inquiry June 2001

⁶⁹ Joseph Rowntree Foundation, The independent care homes sector: implications of care staff shortages on service delivery, Stephen O'Kell, Jan 2002

50% of care workers having achieved at least a level 2 in NVQ care^{7,70} The Chairman of the Kent Care Homes Association reported that Care Home owners did not have the time or the resources to meet these standards.

5.25 The Select Committee heard that in Kent some homes paid for course fees, expenses and staff time whilst the majority paid little towards fees and expenses and expected staff to undertake the courses in their own time. Some homes have organised group training so one member from each home could attend. KCHA also stated that if staff were encouraged to undertake further study the care homes would need support with course fees, training facilities and cover of staff time. The JRF report (O'Kell 2002) 'identified a clear need for interested parties to work together to improve care services for individual client groups, otherwise problems of recruitment and training will remain a major issue within the independent care home sector'. There is an opportunity for all the interested agencies whether commissioners, providers, private or voluntary to pool resources to move this issue forward.

5.26 As already mentioned it is difficult to recruit and retain staff to care for OPMHN with the right motivation and capacity to care. Although the workforce issues of recruitment, retention and training apply across the board of the care sector, in providing specialist care for older people with mental health needs there are some additional considerations. These are

- ensuring staff and management have specific knowledge, skills and commitment for dementia care
- having staffing levels which provide residents with individual attention
- recognising that dementia care is emotionally demanding for staff, managers, and responding to their needs for support
- maintaining good links with local health and social care services, community groups and other local resources.
 - (Source: JRF, Put yourself in my place, C Cantley and C Wilson, March 2002)

5.27 In particular, care staff need a good foundation of training in dementia care to equip them with the skills needed to deliver high quality care. In the later stages of dementia clients become more confused, have reduced comprehension, have difficulties communicating, become increasingly frustrated and can develop challenging behaviours. Care staff need training for example in order to minimise challenging behaviour by understanding the person and having the correct skills to handle behaviours appropriately and successfully. Specialist homes for OPMHN are required to staff on a ratio of 1:4 to meet the needs of a more dependent and demanding client group. KCHT explained that a specialist home needs to find a balance of security and risk management so that the home is not restrictive but allows freedom to express oneself in a safe environment. The idea of in the future having senior night staff to supervise more dependent clients was proposed.

5.28 The importance of the continuity of care was also raised with the Select Committee. Staff management can help facilitate this by routine shift patterns and cover arrangements, providing residents with greater consistency of care.

⁷⁰ Joseph Rowntree Foundation, The independent care homes sector: implications of care staff shortages on service delivery, Stephen O'Kell, Jan 2002

5.29 As an example a partnership of the Brighton and Hove Council, Brighton and Hove National Care Homes association, Age Concern (Brighton) and the Independent care Organisations (ICO) applied to the European Social Fund to provide training for staff in the independent sector care homes. The bid was successful, formally launched on 20 March 2001 and aimed to train 125 care assistants to NVQ level 2 and 50 senior staff as assessors. This gave participating homes the opportunity to have two care assistants and one senior member of staff trained for an NVQ qualification. As discussed in the previous Kent report on domiciliary Care (March 2003), SSD and Local Initiative Funding of £259,000 was secured for social care training initiatives, launched in February 2002 and aims to deliver 100 NVQ at levels 2/3 and 4 across the social care sector. It is hoped that if this project is successful, the Learning Skills Council will release further funds and be matched by bids for European Funding. The KCHA acknowledged the support of SSD to work with the sector to improve the issue of training. Care staff across the social care sector need continued improved access to training opportunities, including those in residential care homes and also home care teams. KCHA suggested the possibility of exploring the idea of having a 'partnership' training officer to work across the sector. Corporate providers could also be encouraged to play a role, perhaps building on the training they currently offer. The Domicillary Care report highlighted the need to improve the care status and career progression for care staff. The Select Committee would like to reiterate the importance of this.

Recommendation: SSD need to encourage ways to provide progressive training in partnership with Health, private care providers and voluntary organisations, and research further funding streams.

5.30 National Care Standards Commission

The National minimum standards established under the Care Standards Act 2000, focus on the structure and process within care homes to improve quality of the services delivered to older people. The new training requirements and environmental standards increase the financial pressures on care home owners, as they require investment to make alterations, (e.g. to increase door widths, install lifts or enlarge rooms). These standards were relaxed after consultation with the care home sector and rising fears that many homes would close. The environmental standards now apply to homes that were established after 2002. All homes need to provide a statement about how they comply with the standards. The NCSC West Kent Area Office told the committee that the standards were a benchmark of what to expect and what to monitor and how to improve services. The key message was that the "only way to improve quality of care is to work together".

5.31 Affordable key worker housing

A further issue that affects staff caring for OPMHN and indeed the rest of the social care sector is that of affordable housing for key workers. A LGA paper concluded that 'high house prices are creating staff recruitment and retention problems, especially in the public and service sectors... Social exclusion is increasing with those on low income, a high proportion of these are likely to be from vulnerable groups and ethnic minorities."⁷¹

⁷¹ Local Government Association - Housing, Key workers and affordable housing, June 2002

5.32 In a recent league table of the least affordable areas, "districts in the South East are among the hardest areas anywhere in the country for young earners under 40 and key workers ... to set foot on the home ownership ladder."⁷² A majority of the 40 worst districts are in the South East region, including Sevenoaks in Kent. In contrast the study also found that the lowest price to income ratios for the South East starter homes are in Gravesham (2.75) and Ashford (2.89) in Kent. This is below both the regional (3.96) and the national average (3.4).

Recommendation: SSD need to lobby national and planning authorities for the recognition of care workers as key workers.

5.33 Activities

Activities play a key role in providing a good quality of life, reducing isolation and often the onset of depression. The promotion of activities, including memory activities, help older people with dementia maintain the skills they have.⁷³ The Personal Social Services Research Unit reported that most care homes organised activity programmes for their clients.⁷⁴ These however varied between sectors and variety of activities and that activities were mostly organised by staff rather than volunteers or professionals. There is a need to facilitate appropriate activities for all residents, including everyday activities such as helping with the washing up or doing some gardening. The importance of activities and stimulation to maintain skills, learn to adjust to dementia and social inclusion have been well documented.

5.34 The Committee heard that there was a lack of stimulation and activity within care homes and although homes organised some activities these were not necessarily suitable for all clients, for example some residents had never enjoyed pantomime and so the annual trip was of little interest. It was suggested that if someone had a particular interest why not match this to a volunteer with a similar interest and the activity undertaken. For example finding a person to play chess with a client who had always enjoyed chess, a keen gardener to garden with someone who enjoyed gardening, matching 'jigsaw' fans together. There was also a reported reluctance of some care homes to involve clients in the everyday activities, such as laying the table for supper or helping with the washing up. An informal carer told the Committee that

"Institutionalisation was encouraged as 30 clones are a lot easier to deal with than 30 individuals who want to live their own sort of life. ...Homes need to be less regimented and more flexible."

5.35 Activities and stimulation could be tailored to individual needs. The findings of *"Put yourself in my place"* stated that older people with dementia benefit from an environment that provides familiar features and scope for involvement in ordinary

⁷² Joseph Rowntree Foundation, Wilcox Steve, Can work – can't buy, Press release – League tables reveal least affordable areas for young homebuyers in the South East, 2003

⁷³ ADSS, Prevention of dependency in older people: Position of ADSS Older People's Committee, accessed at www.adss.org.uk 16/06/2003

⁷⁴ Netten A, Bebbington A, Darton R, Forder J, Care Homes for older people: Vol 1 Facilities, residents and costs, PSSRU 2001

domestic activities.⁷⁵ It also highlighted the need to maintain links with resident's local community as far as possible. Links with volunteers, the voluntary sector and the local community could be established to help meet these needs. It is unclear how many care homes draw upon resources that already exist or if they are aware of the opportunities available. Members discussed the possibility of Adult Education also assisting to meet these needs. It could also be possible to open up activities to non-residents to participate in. The Committee heard that more care staff were needed during the day to increase the amount of activity, stimulation and therapeutic work perhaps through 'Activity Stimulation Posts'. In "Active Care –active lives" Kent gave its commitment to setting standards for residential care which help ensure people remain active. Dementia support workers funded through the building capacity grant may provide some of the extra support required in care homes.

Recommendation: SSD need to create a plan to encourage the development of activities to meet the needs of OPMHN and the individual. This could include partnerships with Adult Education and voluntary organisations.

5.36 It is an accepted view that it is not only social isolation and lack of activities that trigger depression, but also physical problems. A PSSRU study on depression and the response of residential homes to physical health needs found that 79% of the sample (309 residents) had dementia, 40% (of 194 residents that could be assessed) were depressed.⁷⁶ The sample group had 4 main problems, namely mobility (72%), stability (67%), hearing (40%), and vision (46%). The report concluded that response was variable with only 7% of homes responses assessed on care plan quality and key worker awareness rated as good. Good interventions by key workers were associated with less depression in residents. The study suggests "improving this aspect of care might reduce depression and thus improve quality of life". The study indicates that residential homes could do more to support their residents and improve their quality of life. Activities and stimulation play a key part in reducing the risk of depression, tackling isolation, maintaining skills and are particularly important as physical difficulties develop.

5.37 <u>Transfers to different care homes</u>

O'Kell (2002)⁷⁷ found that all of the homes in the study conducted were reluctant to transfer a resident to another care facility if his or her care needs changed, such as developing dementia. Kent care home providers informed members that if a client develops mental health needs whilst in residential care there was a requirement to register that bed place for OPMHN with the NCSC. Care Home providers felt they should be able to continue caring if they were able to meet the needs of the older person. They requested more flexibility in the application of the NCSC standards so that if care needs could be met residents can remain in their current home. The NCSC (WK) agreed with the opinion that relocating people as dementia progressed was not ideal and that specialist OPMHN care homes were needed. However, Members were informed that if someone developed dementia whilst in residential

⁷⁵ Joseph Rowntree Foundation, Put yourself in my place: designing & managing care homes for people with dementia, Cantley & Wilson 2002.

⁷⁶ PSSRU, Mann A, Schneider J, et al, Depression and the response of Residential Homes to physical health needs, 2001, accessed at www.kent.ac.uk/PSSRU/abstracts

⁷⁷ Joseph Rowntree Foundation, The independent care homes sector: implications of care staff shortages on service delivery, Stephen O'Kell, Jan 2002

care they would be able to remain in the same home if the NCSC were satisfied the care home had made the appropriate changes to meet needs e.g. ensuring staff were adequately trained, and had appropriate registration.

5.38 The NCSC (WK) representative stated that in Kent the limited availability of EMI homes (leading to OPMHN being placed in non-specialist homes) and current residents developing dementia, meant homes often needed to make a variation to their registration. For homes not registered to provide services for OPMHN there is an additional specialist bed registration charge of £500, payable to the NCSC. Kent care home owners emphasised their reluctance to move someone to a new home just because dementia was developing, but the registration charge increased the already high financial pressures. It was however acknowledged that if the level of dementia became to high for the home to meet the needs of the person then they should be moved. The Select Committee also heard that some providers put relatives under increasing pressure to pay the home the cost of the additional registration, in order to prevent the relocation of clients.

5.39 Service model / Built Environment

As the demand for specialist dementia places increases there is a need to consider whether to have a specialist home or integrated dementia units, and the extent to which homes will have residents with mixed or similar dependency levels.⁷⁸ The Committee heard a mixture of opinions as to whether residents with or without mental health needs should be mixed together or not. Providers said that residents liked to remain in touch with their friends who may have developed dementia whilst in residential care offering friendship, help, support and comaraderie e.g. walks together. The Chairman of KCHA believed this was feasible with the onset of mild dementia. The NCSC (WK) reported that this seemed less accepted if it was an 'outsider' who was admitted with mental health needs. The Committee heard that other residents however preferred not to mix with someone who developed or entered the home with dementia, not wanting to see 'their own possible destiny', finding being with people with dementia distressing and traumatic. KCHT felt that OPMHN needed different care, with staff able to communicate with someone with deteriorating communication skills and comprehension. A possible solution would be to have enough capacity to give residents a choice, or homes that had mixed provision through separate units with joint and separate communal areas so that residents could choose to mix or not.

5.40 *"Put yourself in my place"*⁷⁹ not only found that older people with dementia benefited from an environment that provided familiar features, scope for involvement in ordinary domestic activities but also one that had good signage with cues for following or 'sensing' a route.

5.41 <u>Support of Care homes/Community nurse support:</u>

As more physically frail and OPMHN are living in residential care the demand for district nursing is increasing. O'Kell stated that of the homes interviewed most

⁷⁸ JRF, Put yourself in my place – designing and managing care homes for people with dementia, Cantley and Wilson, March 2002

⁷⁹ JRF, Put yourself in my place: designing & managing care homes for people with dementia, Cantley & Wilson, March 2002

homes were very satisfied with the level and quality of community nursing services available to residents.⁸⁰ Some health authorities have established 'Elderly Liaison Teams' to provide advice, support and training to care homes. As prevalence of dementia and demand for specialist homes increases in Kent so to will the need for more support from Community nursing services, with specialist knowledge of caring for OPMHN.

5.42 Out of area placements

Issues concerning out of area placements are twofold. Firstly, Members were concerned with the impact of out of area placements on the availability of bed places in Kent residential care homes. London Borough's can place clients in Kent at a lower rate than in their own Boroughs' and pay a rate higher than the KCC contracted rate, enough to attract providers away from Kent Contracts.

5.43 Secondly, due to lack of availability sometimes Kent clients are placed out of area. Members heard concerns from one carer that SSD do not know the suitability of care homes out of area before carers are sent to view them. In this example on visiting the home it was clear that the home was unsuitable to meet the specific individual needs and that SSD had not made a prior visit to the home to check suitability before sending relatives to view. The placement was further unacceptable due to the distances that would have to be travelled by the carer. The volunteer bureau was only able to offer a visit for the duration of 30 minutes once a week. This was unacceptable to the carer who felt due to lack of availability they would be pushed into agreeing something that did not meet everyone's needs. SSD were informed of the concerns on the issues raised by the witnesses for investigation.

5.44 Development Planning

Kent care home providers reported that they were not fully involved in the development and planning of services, including services for OPMHN, however it was acknowledged that providers could currently meet with Kent officers to discuss issues and find resolutions. There was a desire to have greater involvement in a more structured planning process, but also recognition of the difficulties in achieving this. There was common agreement that it would be a good idea to explore the possibility of involving both private home owners and the voluntary sector in the '4 year' planning process, perhaps through a recognised body such as the KCHA. KCHA supported this view, expressing a wish to see the private sector involved in more forward planning, contributing to longer term SSD plans. The NCSC believed services for OPMHN needed to be more structured with fewer one off placements, with structures that allow dementia to develop, without the need for relocation.

5.45 <u>The future</u>

There needs to be provision of an environment in which people can contribute their best in the care home setting e.g. through supporting staff of nurses, carers, support workers and ensuring adequate resources. As mentioned in 5.6 care homes could branch into rehabilitative care. This view was also shared by the chairman of the

⁸⁰ Joseph Rowntree Foundation, The independent care homes sector: implications of care staff shortages on service delivery, Stephen O'Kell, Jan 2002

KCHA, who suggested that in the future care homes could provide some of the 'stepup step-down' facilities. This type of facility has emerged in one area of Kent. In Chapter 6 the opportunity to use existing residential care homes for recuperative care is highlighted. The Committee would like to endorse this policy and encourage its development where appropriate. For such diversification in the future to be successful and effective there would need to be support from Health teams set up in consultation with the private and voluntary sector. Residential care needs to develop into a positive, quality option that could envisage people returning to the community and not seen as a permanent place or step before nursing care. This would require a large cultural change and resource shift, but might offer a broader role than just providing specialist residential care.

CHAPTER 6: CARE AT HOME

6.1 Residential care is not the only option for people finding living at home difficult. Many older people carry on living at home with extra support. Sheltered Housing is another possibility. Government policy has put care within the community for older people as a high priority for care provision. The key objectives of Caring for people reforms (1993) were to promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and sensible. Similarly, the NHS Plan outlined the development of services for older people to minimise admissions to residential care and hospital, support early discharge, reduce bed blocking and advocated the development of intermediate care services to ensure rehabilitation and prevent loss of independence. Within Kent SSD there is a continuing acknowledgement that older people usually prefer to remain in their own homes for as long as is feasible, and increased effort to make this possible with the development of innovative and effective services balanced in favour of home based care. The current increase in home based provision has been reported in the KCC Annual Plan 2003. "Active Care – active lives" states that Kent

" will work closely with our social care partners to make this a reality, to enable people to ... live safely and independently in their own communities...we will ensure that older people have the support to stay in their own home if this is what they want...by

- extending recuperative care and rehabilitation across Kent
- reinstating preventative domiciliary care services
- providing more intensive home care ..." (Source: KCC 2003⁸¹)

6.2 <u>Prevention and Health Promotion</u>

"Respect for old age" emphasised that there should be greater focus on delaying the onset or progression of illnesses or dependency that lead to a need for long term residential care.⁸² It argues that health promotion is an important aspect of government policy and is equally important to older people and maintaining their independence. Prevention services provide support or skills that focus on maintaining independence and stopping or delaying the need for long term residential care. Intensive home support models need to be underpinned by Health and Primary Care Trusts. Health and social care (in partnership with voluntary organisations) need to work, plan and develop as an integrated service, and include specific focus on the differing needs of people with dementia.

6.3 Low level preventative services

The effectiveness of "low level" services in preventing the onset of dependency has also been recognised. Major studies agree that help with housework, gardening, laundry, home maintenance and repairs helped maintain older people at home and enhanced their quality of life, and that these services are central to the well being and

⁸¹ Kent County Council, Active Care – Active lives, A new look at socail care in Kent: A ten year vision, 2003

⁸² Royal Commission on Long Term Care, With respect to old age: Long term care – rights & responsibilities, 1999

confidence of older people to cope at home. As stated in Chapter five the inability to keep a well-maintained home was a key factor contributing to the admission of older people to long term residential care. Research has shown that low intensity support can help prevent people reaching crisis and enable them to sustain their own homes.⁸³ The Select Committee heard that these types of services are highly valued by older people and their carers, who may also be elderly. It can be argued that if dependency is delayed by the provision of these services so to is the need for more intensive support. There is a need to encourage the provision of these low level but important services. The Select Committee expressed concern that the over regulation of these services could impact on their availability and accessibility.

6.4 <u>Domiciliary services</u>

The number of domiciliary care hours provided has increased in recent years to meet changes in policy direction. As the number of hours have increased, the number of people receiving the service has reduced, suggesting a more intensive package of care to clients with higher levels of need.⁸⁴ "Over the threshold" considered whether older people could be supported at home as they became more frail and mentally impaired. It concluded that with appropriately tailored services this was feasible and that intensive domiciliary support made this an efficient and effective option, and gave broader choice to older people.⁸⁵

6.5 ADSS raised concern regarding the low level of training and skill base of staff working with elderly people, the majority of which is within the private sector, and the ability to ensure staff working with older people with dementia have the training opportunities and the skills required.⁸⁶ There is a need for specialist home care workers to meet the needs of OPMHN. The staff expressing an interest in developing skills in this area should be encouraged and supported to do so.

6.6 Kent SSD has established an inhouse 'Dementia Home Care scheme' for older people with dementia. This service is generally only commissioned for older people living on their own. If the older person is living alone there is more responsibility placed upon the care worker, undertaking more of an assessment role and alerting the care manager/multi disciplinary team as necessary. The Select Committee heard that the possible risks of an older person with dementia living alone are normally considerably higher than for someone who has a carer living with them. If there is a resident carer the standard domiciliary service is usually commissioned. At the time of this review there were ten people who lived alone receiving the 'Dementia Home Care Service'. These individuals had high levels of need and were continually assessed.

6.7 For someone living alone with dementia residential care is sometimes seen as the only alternative unless services can be broadened to meet the needs of the person. Provision for OPMHN is expanding in the residential care sector but this

 ⁸³ Joseph Rowntree Foundation, The importance of 'low level' preventative services to older people, July 1998
 ⁸⁴ Department of Health, The residential care and nursing home sector for older people: An analysis of past

trends, current and future demand, 2002

⁸⁵ Scottish Executive, Over the threshold? An exploration of intensive domiciliary support for older people, March 2003

⁸⁶ ADSS, Not Forgotten, A report by multi-professional group for better services for older people with dementia, accessed at www.adss.org.uk 22/05/2003

needs to be matched by development in the dementia home care sector. It was estimated that there were also 100-150 people with dementia in receipt of home care living with their carer. Domiciliary care is also needed for OPMHN who do not live alone and who often do not receive the same levels of support as someone who lives alone, giving support to their carers. This support could emerge as non-traditional respite, but support at home enabling carers to have a break. The ability of domiciliary care services in Kent to meet the needs of OPMHN is variable and depends largely on the quality of the care force and their willingness to work with a challenging and demanding client group, and not all care workers are comfortable caring for OPMHN. The salaries of care staff who provide support for OPMHN do not reflect the additional responsibilities, experience or training required. The Select Committee heard that Independent providers said they would not guarantee that any guaranteed extra fees for competency and skills to meet the needs of OPMHN would be passed on to care worker salaries. For the private sector to follow suit of the Dementia Home Care Service on a large scale will require a joint initiative. Specialised training is an area that is much needed for all who provide home based support, including care and repair services, and could greatly improve the quality of services delivered. This should include dementia awareness, social impact and diversionary behaviour training.

6.8 It is recognised that OPMHN patients become increasingly confused and vulnerable on admission to hospital and that an alternative form of care on discharge was required. Dartford, Gravesham and Swanley Primary Care Trust commissioned discharge from hospital supported by specialist care packages from an independent home care provider. This was limited by the difficulty to find specialist domiciliary staff for OPMHN. The Trust has proposed a new dementia care community service. A pilot of this service showed that it was effective, resulting in only one OPMHN being admitted to residential care.

6.9 <u>RED – rural emergency and hospital discharge service</u>

In Mid Kent problems were identified obtaining domiciliary care packages for rural areas to enable discharge from hospital. Providers suggested 'RED', which bought blocks of hours for double handed shifts for staff covering rural visits, as need arose the service would then go to where they were sent rather than trying to set up new packages each time. There are increasing requests for double handed visits which will need to be taken account of in developing services in the community for OPMHN.

6.10 Intermediate Care

Intermediate care is central to the government care strategy for older people. It promotes independence, reduction in delayed discharge and the avoidance of unnecessary admission into long term care. These services are broad in both nature and the settings in which they are provided, including from home to hospital. ADSS stated that although the concept of intermediate care is excellent it is not ideally suited to older people with degenerative conditions, such as dementia. Recuperative or rehabilitation is more useful for people with dementia, although current services need to alter to reflect the different care needs of OPMHN and focus on the reablement and maintenance of skills for as long as possible.

6.11 <u>Rehabilitation and Recuperative Care</u>

Pressure to reduce delayed hospital discharge and the rate of admission into residential care, and the need for appropriately timed assessments led to the development of recuperative care services. The need to provide an opportunity for rehabilitation prior to assessment on discharge from hospital or after a crisis is now widely recognised, enabling assessments to be undertaken when an older person's condition has stabilised and function (mental or physical) has been restored as much as possible. It is accepted that proper time for convalescence and recovery could reduce the need for permanent residential care and can extend the period someone can live independently at home or with support. This is especially important for OPMHN who can experience higher levels of confusion due to effects of being ill, away from their normal home and routine and in an unfamiliar place. Placement in residential care should therefore only occur after the potential for rehabilitation or stabilisation has been explored.

6.12 The Royal Commission stated that the development of rehabilitation services had been innovative across the Country but many had denied access to older people living in residential care homes (or OPMHN).⁸⁷ The Select Committee heard that Kent schemes had developed in response to district and area need and opportunities arising, and therefore these varied considerably according to geographical area. These schemes had successfully reduced both delayed discharges and the rate of admission to residential care. Rehabilitative/recuperative services for OPMHN in Kent were however less developed to non-existent. OPMHN need access to specialist services designed to help them regain and maintain as much independence as possible and the ability to return home rather than entering residential care.

Recuperative Care services are vitally important to enable many older people 6.13 return home successfully rather than enter long term care. This opportunity should also be available for OPMHN. The Kent OPDSU currently provides 14% of their beds for recuperative care, based in Linked Service Centres. There were currently no specific services targeted solely for older people with dementia. The Select Committee heard that private providers were often reluctant to set up services that had business risks attached, such as recuperative beds due to possible low bed occupancy rates. The in-house service therefore often pilot services for more complex client groups or new ideas. The recuperative care service has been very successful. In 2002/2003 87% of people returned home to live independently after recuperative care, and many had returned home with minimal support or packages lower than they had prior to admission. These services now need to reflect the needs of older people with dementia as current schemes tend to focus mainly on physical needs to regain functional skills for daily living and there is a clear gap in provision of services for OPMHN and services which focus on maintaining skills.

6.14 The Occupational Therapy and Sensory Disability Unit (OTSDU) is working with East Kent PCT to develop a package of Intermediate care for OPMHN, as there is a need for development of services around dementia. However the current funding of recuperative care is due to end this year and will therefore need allocation from

⁸⁷ Royal Commission on Long Term Care, With respect to old age: Long term care – rights & responsibilities, 1999

elsewhere. In Mid Kent the high levels of admission to residential care in Ashford, lack of local recuperative care and local centres able to offer support led to the establishment of an innovative and very encouraging recuperative scheme with a private residential provider. 'Private Care' offers recuperative care within a residential care home with the apeutic support from Health, using the natural environment of the care home to practice skills. Out of 30 older people admitted 87% went home, 57% had no care package and only 2% were admitted to residential care. This area now has one of the lowest placement rates in Kent. The private provider was responsive and flexible to meet local needs and adapted the building to incorporate areas for making snacks and drinks. This initiative could be expanded so that a cluster of homes could have recuperative care beds supported by CART teams, enabling older people to be supported in their locality. Care Homes for this scheme need to have a stable workforce and good levels of training, also 'small is beautiful' and could be operated very successfully by smaller homes depending on the owner and their motivation. One difficulty was finding G.Ps to take on temporary residents and others have closed their lists. If services were based in localities then someone's own GP would continue to oversee their care.

6.15 If recuperative services could be set up in partnership with care homes, offering guaranteed occupancy levels or block bed rates, some of the reluctance to offer this type of service might diminish within the independent sector and number of available beds increase. Interestingly Richardson (2002) stated that current provision

"... as an example of partnerships is disappointing. The DOH tells us there are some 2,400 intermediate care beds in operation today but only a minute proportion of these are being provided by the independent sector. ... This really is a missed opportunity."

(Source: Richardson 2002)⁸⁸

6.16 Residential care homes have an opportunity to broaden their service base and need to consider whether to expand services and incorporate recuperative as well as respite places or day places. KCHT informed the Select Committee that this type of service was something residential care homes could provide given the opportunity, encouragement and support to change.

Recommendation: The opportunity for recuperative care should be extended and encouraged for all older people with mental health needs either as a separate service or within mainstream service.

Recommendation: SSD should ensure recuperative care services are developed equitably across the county, using the private and voluntary sector if appropriate.

6.17 Intermediate/Recuperative care services are essential to promote the ability of older people to return to live at home and leave acute settings as guickly as possible. and normally comprise of a short intensive package of 6 weeks duration. There is a fear that some older people at risk of admission to long term residential care (particularly OPMHN) may be excluded from the benefits of this service as they may

⁸⁸ Richardson Frank, Latest Developments in the Long Term Care Market, Annual LTC for older people conference, March 2002

need longer than the 6 week period to recover. It is argued that this results in a premature decision to enter residential care as outcomes are not clear and often therapy ceases while a place is found.⁸⁹ The South West Kent recuperative care project in partnership with Health is a good example of joint assessments and links three stages of care. Stage 1 is for up to 8 Weeks of rehabilitation therapy, Stage 2 for up to 6 weeks of intensive domiciliary care to build on stage 1; and Stage 3 for up to 38 weeks of domiciliary support, reducing in intensity over time. The scheme however does not reflect the specific needs of OPMHN.

6.18 <u>Support at Home Service/Rapid Response Service</u>

If a crisis occurs at home, intensive support from a multi-disciplinary team could help avoid unnecessary admission to hospital and residential care, supporting the crisis and providing a robust 'community care' plan. Between January 2003 and June 2003 the Ashford based Health/SSD Rapid response team assessed 155 people of whom 63% avoided hospital admission and 19% avoided admission to residential care.

6.19 Kent in partnership with West Kent NHS Trust and South West Kent PCT have submitted a proposal for 'support at home service' pilot project for OPMHN.⁹⁰ This would provide a rapid response service capable of responding to demands instantly rather than days, taking in Tonbridge, Tunbridge Wells and Sevenoaks Districts. It acknowledges the role of carers and the importance of services that can offer timely response particularly for OPMHN. Services within South West Kent PCT area have demonstrated the effectiveness of schemes in maintaining people in the community, reducing emergency demand for acute beds and ensuring appropriate and timely placements are made. Delayed transfer figures for OPMHN in Mid and West Kent indicate that 1596 bed days are lost at a cost of £520 per bed per week. The scheme aims include to

- avoid inappropriate placements
- assess mental health needs in a crisis
- offer an alternative to hospital
- provide high quality social care in the community supported by a range of secondary services (for up to 6 weeks),
- respond to users and carers needs and
- work with established providers to develop a training package for domiciliary staff to be involved in the 'set down' service

This will be achieved (if the proposal is approved) by 'Rapid response teams', effective joint agency liaison, an extended service hours (8am – 8pm, seven days a week), counselling and telephone support to carers. A key part could also be played by voluntary organisations but their input would need to be financially supported.

⁸⁹ Department of Health, Changing places: report on the work of the Health and Social Care Change agent Team 2002/03, July 2003

⁹⁰ Kent County Council, WK NHS Trust SWK PCT, A proposal for a pilot project for a support at home service for older people with Mental health difficulties, March 2003

6.20 <u>Community and equipment services</u>

"Fully Equipped" predicted that almost a million people need equipment to help them live independently.⁹¹ This concluded that there were long delays in receiving equipment and that this was often of a low quality. These services are vital to support both government and Kent's local policy objectives to promote social inclusion and independence and ensure people could remain at home. A timely response to both assessment of need and provision of equipment increases the ability of OPMHN to remain at home for longer, assist with hospital discharge and reduce the rate of admission to residential care.

6.21 There are Occupational Therapists (OT's) within the Health Service and social service departments. KCC OT's in the OT and Sensory Disability Unit (OTSDU) play a key role helping older people live independently and in transition from hospital to home. Despite national shortages of OT's, Kent recruitment has been maintained with shortages currently only in Dartford and Gravesend. During 2002/2003 the team received 11, 367 referrals across the county, and demand for services is increasing. The OTSDU occupational therapy reports are incorporated as a vital part of the care management process. For instance prior to discharge from hospital an older person should expect an assessment to ensure they can manage at home, the necessary equipment and services to be in place and adaptation work agreed and arranged. By April 2004 the unit will have integrated with care management staff to establish district based 'promoting independence' teams.

6.22 The "ICES agenda" is to streamline services and delivery using pooled budgets. The integrated community equipment service, encourage single procurement bringing with it savings by purchasing through the same supplier. Kent currently purchases through County Supplies (linked through the Consortium) and could see PCT's having access to this in the future. It was also noted that funding for specialised equipment was in a shared budget with PCT's, however contributions were not equal and needed reconsideration. With systems becoming increasingly integrated and shared budgets there was a need for single inventory systems, as users were often difficult to track and communication complicated.

6.23 It is argued that OT assessment can often be based on a snap shot in time informing judgement on functional ability and equipment or adaptations needed, with time pressures leading to prescriptive recommendations. It was highlighted that during home visits prior to discharge from hospital older people can feel anxious and this is intensified for older people with MHN, as this is an emotional experience to see 'home' and undertake tasks in front of a stranger. These are often perceived as a test 'pass or fail situations'. Kent home care are carrying out assessments over several visits for OPMHN so that a clearer picture can be obtained and a better relationship established so assessments are more relaxed for the older person.

6.24 Integrated equipment services are expected to deliver services to 50% more people (a total of about 18-20,000 for Kent). In addition there are also two new targets to be implemented by 2004 that affect the OT service. These are that

• all people should be assessed within 4 weeks of referral

⁹¹ Audit Commission, Fully Equipped 2002: Assisting Independence, 2002

 all necessary equipment needed by the individual should be provided within 7 days of the decision of assessment, including all minor adaptations

6.25 A proposed action plan has been put forward to implement these over a 3 year period (2004-2007). Achieving these targets has a large resource implication for the Kent OT's who face difficulties due to rising numbers of referrals increasing demand and assessments taking around one and a half hours. This means that the current service would be too expensive to provide for everyone and difficult to achieve. A benchmarking exercise with other Local authorities showed other Counties were also having difficulties in reaching the new targets. It was acknowledged that to gain maximum benefit older people needed timely services and equipment as soon as possible. The unit recognised the need to focus on how to deliver services differently, and adapting support provided by Home Improvement Agency staff and Handy Person schemes could help resolve the situation. The idea was to set up a telephone assessment/referral service so that if people new what they needed this could be requested direct with HIA staff trained to answer questions about the equipment and competence to work it. It is anticipated that this option would save money and help meet the increasing demand for OT services. Liaison with the Health authority would play a major part in the ability to achieve targets through better integration.

6.26 A further difficulty for Kent is the location of equipment stores. Currently there is only one SSD store and seven Primary Care Trust stores, making it difficult to reach all parts of the county quickly. The Committee heard that the intention was to move towards having services based on the four Health Economy areas.

6.27 KCC OT's had also needed to respond to specific needs of older people with dementia or mental health needs. Specific training plays an important role and is vital for OT's and carers working with OPMHN, including health and safety training regarding equipment use and maintenance and training of dementia awareness and specific dementia therapy techniques. Within the career structure it was also possible for rehabilitation co-ordinators to become a qualified OT by following a four year part time course. The Select Committee endorse the recommendations of the recent Best Value Review of Adult Services.

Community Equipment Services and the use of assistive technologies (telecare) are discussed separately in Chapter 9.

6.28 Care and Repair Services and Home Improvement Agencies

Care and repair services (and Staying Put Schemes) offer advice and assistance to older people, offering practical support and helping them to carry out repairs and maintenance to their homes and help prevent unnecessary entry into residential care. They 'improve homes to improve lives'. The inability to undertake adaptations quickly is a contributory factor to people entering long term residential care and the timely response and provision of aids and adaptations enabling OPMHN to remain at home is therefore clearly important. In Kent and Medway there are 12 Home Improvement Agencies that cover all authority areas. If increasing numbers of older people with mental health needs (and older people) remain at home, support from these local 'care and repair or handyman' services will need to develop and expand and provide a streamlined service reducing the trauma of multiple visits. These services also need to be readily accessible by care managers so that quick interventions can be

put in place. Housing Corporations also often have schemes established for their residents. These existing schemes could possibly be extended to the wider community in partnership with Housing, Health and Social Services and existing care and repair schemes.

Recommendation: SSD to explore the opportunity to extend and develop current care and repair services to the wider community as appropriate in partnership.

6.29 Home Improvement Agencies and care and repair services in Kent were increasingly required to deliver services for older people with dementia and that staff within these agencies had expressed concern that training and information was needed to help them develop skills in working with people with dementia. Key areas suggested were the nature and effects of dementia, specialist technologies (e.g. telecare) and techniques to cope with differing behaviours. This is important if care staff are to provide a quality service that understands and is responsive to needs of OPMHN. Training or workshop opportunities need to be developed and if possible existing resources used, perhaps in partnership between Health, PCT's, Housing and Social Services drawing on experience of staff already working with OPMHN.

Recommendation: SSD should encourage the establishment of partnership plans to provide dementia training that would assist Home Improvement Agencies and care and repair teams work effectively with OPMHN.

6.30 <u>Befriending services</u>

Older people supported by community care services are frequently socially isolated and this influences decisions to enter long term care. Carers also become increasingly isolated loosing touch with their social networks. Voluntary organisations have developed 'befriending services' to promote social interaction and involvement as part of a community. In similarity to the discussion on activities in Chapter 5, the matching of volunteers and users is key. This type of service can provide support and opportunities for social activities and communication. The possibility of these services could be explored for OPMHN at home as well as within residential care settings.

Recommendation: SSD should encourage the development and/or establishment of schemes focusing on social inclusion of OPMHN and their carers where required.

Recommendation: SSD need to consider the capacity needed in all services contributing to the home based support model to ensure that people with dementia can access timely, responsive and effective care.

CHAPTER 7: CARERS, RESPITE AND DAY CARE

7.1 Britain has an estimated 5.7 million carers. It is widely acknowledged that informal care arrangements are a vital part of support for people with dementia. The Alzheimer's Society estimates there are 700,000 people in Britain suffering from dementia and that the majority are cared for by informal carers, many of whom are elderly themselves. *Caring for people* reforms aimed to ensure that service providers made practical support for carers a high priority. This objective has been achieved to a limited degree, the profile of the work of carers is increasing, yet support to carers is variable and can overly depend on where people live or the care manager they are allocated.⁹² PSSRU found that future trends in the availability of informal care are likely to have considerable implications for demand for formal care.⁹³

7.2 <u>Strategy for Carers</u>

"Caring about carers" is the national strategy for carers.⁹⁴ The three key strands to the strategy are better information for carers, better support for carers and better care for carers. Some local authorities have published 'A Joint Carers Strategy' or a carers plan, setting out how the authorities intend to accelerate improvements in practical support for carers across their county, and involved carers (through workshops), voluntary organisations and the statutory sector in its development, for example Devon County Council and East Surrey County Council. Kent SSD have shown their commitment to developing a new strategy for working with and supporting carers, and are undertaking a piece of work to underpin this by giving an accurate profile of information on carers in Kent. Furthermore *Not Forgotten* recommended that emphasis should be given to ensure a specific strategy for carers of people with dementia, clearly identifying helplines, information, support and respite availability in each locality.⁹⁵

Recommendation: As a high priority SSD should develop both a carers strategy and a strategy for carers of people with mental health needs including dementia.

7.3 <u>Carers needs</u>

People with dementia are not the only people affected, but also those who provide informal care. The role is complex, demanding and changing constantly to meet the needs of the different stages of dementia. Carers often provide 24 hour care and may become increasingly anxious, depressed or have insomnia. Armstrong (2000) ⁹⁶ identified the key reasons carers feel they can not continue caring and place relatives in residential care as wandering, lack of sleep, aggression, incontinence and physical

⁹² Warburton and McCracken, With Respect to Old age – Research Volume 3, Ch.2 An evidence-based perspective from the DOH on the impact of the 1993 Reforms on the care of frail elderly people, 1999

⁹³ PSSRU, Demand for Long term care for older people in England to 2031, LSE and U of Kent 2001

⁹⁴ Department of health, Caring about carers –the national strategy for carers, 1998

⁹⁵ ADSS, Not Forgotten Report by multi-professional group for better services for people with dementia, accessed at www.adss.org.uk 22/05/2003

⁹⁶ Armstrong (2000) Factors affecting the decision to place a relative with dementia into residential care. Nursing Standard. 14, 16, 33-37. cited in Royal College of Nursing, The pressures felt by informal carers of people with dementia Jan/vol15/no17/2001.

dependency. The fear of 'risk of harm' is also a key factor. Nolan (1996)⁹⁷ states that supporting informal carers is crucial as they provide the majority of long term care. It is therefore important to provide support for informal carers either individually or through support groups and be aware of factors influencing the stability of informal care arrangements.

7.4 Influential factors include the carer's personality, coping strategies and relationship with the dementia sufferer. Studies have shown that access to social networks and supportive counselling seem to greatly reduce carer burden, especially if they understand the situation and effects of dementia. Mittleman et al (1996)⁹⁸ found that provision of support and counselling for informal carers delayed admission to residential/nursing homes (particularly for people with mild and moderate dementia), by an average of 329 days. *Caring for carers*, the national strategy for carers highlights research findings that carers are helped to care and continue caring by having time off from caring, relief from isolation, receipt of reliable and satisfactory services, information and recognition of their role and contribution.⁹⁹ The needs of carers are very individual to each case and vary enormously, therefore support services need to listen to carers themselves, be flexible and involve carers and users in their development.

7.5 Information Needs

The stability of informal care supporting a large proportion of older people with dementia is dependent on social networks and effective support and access to a variety of information. Information is important because "without well-informed carers and users, the services will not be supportive"¹⁰⁰, and people need information so they can make informed choices and decisions. It is recognised that if support is given to carers in the early stages of the illness it is likely that the cared for would remain at home for longer. It is vital that after diagnosis the informal carer and the older person with dementia are made aware of the available support and are able to access an adequate level.¹⁰¹ Carers need both written and verbal information as well as emotional support.¹⁰² Information and advice is needed about the dementia, coping techniques, adjusting to the diagnosis of dementia, the implications for carers, available services and benefits. Information needs to be accessible, relevant and comprehensible. There are many organisations and services that offer advice, support or information to carers including the Alzheimer's Society and Dementia Voice. Carers advised Members that the difficulty often lay in knowing where to start and how to access the appropriate support and that limited assistance was given at diagnosis. Despite investment in information, many leaflets do not reach the public and users. Members also heard that many agencies were relying more heavily on the web to disseminate information. Although the Internet and World Wide Web offer

⁹⁷ Nolan 1996, Supporting family carers: the key to successful long term care? British Journal of nursing 5, 14, 836, as cited in Royal College of Nursing, The pressures felt by informal carers of people with dementia Jan/vol15/no17/2001.

⁹⁸ Mittelman M et al. A family intervention to delay nursing home placement of patients with Alzheimer disease. JAMA 1996, Journal of the American Medical Association 276, 21, 1725-1731, accessed at www.minervation.com

⁹⁹ Department of health, Caring about carers –the national strategy for carers, 1998

¹⁰⁰ ADSS, Modern Mental Health Services Need Information Support, accessed at www.adss.org.uk 03/04/2003 ¹⁰¹ Royal College of Nursing, Armstrong M (Nov 2000) The pressures felt by informal carers of people with dementia, Nursing Standard Jan/vol.15/no17/2001

¹⁰² Audit Commission, Forget Me Not: Mental Health services For Older People, 2000

many opportunities, those who do not have access are in danger of being marginalised, therefore other forms of information should not be overlooked or ignored.

It is often argued that GP's and other primary care staff should provide 7.6 information, support and competent advice. Maidstone carers highlighted the differing levels of response from GP's in recognising and offering support to people with dementia. It was highlighted that some GP's still believed there was nothing that could be done for someone once dementia was diagnosed. Evidence has shown that GP's with social care support are more confident in early diagnosis and that information regarding local services should be distributed to GP surgeries. Not Forgotten highlighted that a multi-agency information strategy and funding for information needs to be an essential part of joint commissioning and joint investment plans.¹⁰³ The Kent target to provide support from a social worker in every GP practice that wants support could help tackle some aspects of this issue. A social worker, with training in mental health needs could for example look after a cluster of practices and provide advice and support to carers, GP's and older people with dementia. Maidstone carers agreed this would be useful and a good idea. It is possible that this type of support could also be provided by a Nurse or Support worker, with training in mental health needs.

Recommendation: SSD to actively promote the use of social workers with training in mental health needs to support local GP practices.

7.7 Access to independent and comprehensive information is key to delivering a person centred approach to long term care. Information on the full range of care provision, housing needs, aids and adaptations, leisure etc could be provided from one point, acting as a local guide for older people. The Department of Health good practice examples for person centred care highlighted "*A guide to services for Older People in Thanet*" written in partnership and bringing information, advice and contact details from different sources together.¹⁰⁴ It was noted that to remain effective guides such as this would need regular updating and be a 'living' document.

7.8 Admiral Nurse Service

The Admiral Nurse Service provides specialist nursing support for carers of people with dementia, giving emotional and practical support and advice to carers. Admiral nurses are qualified mental health nurses with additional dementia care training. Admiral nurses can also provide training, information or advice for health professionals and anyone involved in the care of people with dementia and work closely with community psychiatric nurses, and voluntary organisations. Ideally a carer is referred to the service at the time of diagnosis. The Committee heard that this was not always the case. Many carers are left relatively in the dark, until through their own searching find a service e.g. Maidstone Carers that can offer support and advice on other useful services and organisations. Kent carers regarded the Admiral Nurse service very highly.

¹⁰³ ADSS, Not Forgotten Report by multi-professional group for better services for people with dementia, accessed at www.adss.org.uk 22/05/2003

¹⁰⁴ KCC, The Island Guide, accessed at www.theislandguide.org, 2003

7.9 Communication

As already stated the involvement of carers and older people with dementia to develop effective services is very important. Kent SSD Active Care - active lives supports public involvement and the establishment of user/carer/staff workshops. Kent need to consider how older people with varying stages of dementia can be engaged within consultation and monitoring processes.

7.10 Effective communication is one of the most important skills carers (and care staff) can develop in caring for an older person with dementia. Armstrong advises that there should be a "willingness to respect the time and pace of communication".¹⁰⁵ A representative of the Alzheimer's society advised the Committee that communication with people who have dementia can not be rushed, and that carers (both formal and informal) need to be open to non-verbal communication.

Evidence has shown that with support people with dementia can express 7.11 opinions about services and that communication is fundamental to good care¹⁰⁶. The research explored how staff could encourage people with dementia to express their views and preferences regarding their care as part of day to day practice and user consultation in care settings. For example resources such as pictures, word cards and objects stimulated conversation and interaction. The research also highlighted that more time was needed for reflection and discussion during the day, enabling staff to share ideas. It concluded that staff often found it difficult to spend time communicating, consulting and following up plans. Communication and consultation also needed to be developed on an individual basis given variability of characters, effects of dementia and settings. The Alzheimer's society has also carried out some work on consultation processes that include people with dementia. Care staff require support in order that good communication and consultation can be encouraged. These skills will be useful to develop in all care settings for OPMHN, whether at home with carers or care staff or in residential care.

7.12 Respite Care

A key objective of government policy is to ensure promotion of development of respite and day services to enable older people with dementia to live at home where feasible. Carers need their own time and space and a break from caring. This can be provided by day or respite care. Being able to have a break is important to enable carers to continue caring, but can sometimes be incredibly difficult to find. Services need to provide specialised and sensitive support and can be provided by local authorities, voluntary or carer organisations. Respite or 'short breaks' can vary in length from a couple of hours to a week and take place in a variety of settings including carers own homes, residential care homes and KCC linked service centres. The provision of respite is diverse in both providers and settings, complicating access for carers. The Select Committee heard that informal carers had initial difficulty in accessing respite care due to lack of information available about existing respite

¹⁰⁵ Armstrong (2000) Factors affecting the decision to place a relative with dementia into residential care. Nursing Standard. 14, 16, 33-37. cited in Royal College of Nursing, The pressures felt by informal carers of people with dementia Jan/vol15/no17/2001. ¹⁰⁶ Joseph Rowntree Foundation, Exploring Ways for staff to consult people with dementia about services, 2001

schemes or the variety of possibilities, and also accessing adequate amounts of respite. Often knowledge was from word-of-mouth or from carer organisations such as Maidstone Carers. "*A real break*" ¹⁰⁷ reported that some authorities had considered establishing a 'short break bureau', which would act as an agent for both voluntary organisations and their own services. The report states this could be a good model if it emphasised the need to offer choice and sensitivity to individual needs of clients. Carers felt that a 'one stop shop' for information would be very useful and beneficial.

7.13 Informal carers of OPMHN stated that they needed to balance their need for respite with the effect of respite in unfamiliar surroundings adding to confusion and orientation difficulties. If respite is provided regularly in the same location with continuity of care, the break can be built into part of the normal routine, minimising confusion. Also if the building in which respite is provided is sympathetically designed to meet needs of OPMHN this can assist the user immensely e.g. cues for sight, sense and touch. The OPDSU recognise that some buildings can increase the agitation of OPMHN and that the unit needs to work in the future to develop the existing stock. There is a great deal of research/guidance on the design of buildings for OPMHN, some of the ideas of which could be of benefit not only in respite provision but also in residential care homes.

7.14 The Older People's Direct services Unit (OPDSU) works alongside commissioners to deliver PSA/N4Y targets, assisted partly by their respite care (and recuperative care) services. In Kent OPDSU 10% of beds are set aside for respite and 2 % for OPMHN (about 12 beds). Two thirds of OPDSU business remains focussed on permanent care but this is likely to change over the next 2 years, refocusing on increasing respite or transient provision. The OPDSU is also working closely with Primary Care Trusts to develop dementia care centres in partnership in East Kent (Victoria House and Westview).

7.15 Respite in Kent can also be provided at home either during the day or sitters provided at night through a 'sitting or night service' so that the carer can sleep or have a break. Maidstone Carers underlined the benefits of 'home respite' for people with dementia, as the more traditional respite service away from the home was mostly only beneficial in the early stages of dementia. This type of home respite service is generally very popular and effective, however this type of service was limited as the one on one care by a waking member of staff or anti social hours involved meant the service was expensive to provide.

7.16 Carers felt that home respite for a few hours offered excellent support, but hoped this service could be more regular and for longer periods. Maidstone Carers reported that although Crossroads had offered a 3 night sitting service at home funded through a lottery grant, enabling carers to go for example to their sons' graduation or a family wedding, the grant had ended and so the service was no longer available. As wandering, and carers insomnia and lack of sleep are often a key reason for admission of OPMHN to enter residential care, it can be argued that if a carer can be offered respite so they can sleep they will be more able to cope and care for longer. It was acknowledged that it could be possible to establish homes where four or five people would go for respite on a regular basis to enable carers to

¹⁰⁷ Weightman G, A Real Break, 1999

have a regular good night sleep, building this into a familiar routine to limit confusion of OPMHN. Age Concern run a scheme similar to this in Bexley which collects people and takes them to a central unit for a social evening, supper and sleep, allowing carers to rest for a few nights a week.

7.17 Care homes in Kent do provide some respite but this is limited, with fewer opportunities for OPMHN. Although these opportunities exist they are for mainly short periods rather than regular breaks each week. To enable OPMHN to use these services they need to be incorporated as part of a regular routine and staffed appropriately. The increase of demand for special OPMHN homes could further limit availability, unless a proactive step is taken to ensure that this type of service can be provided to offer breaks for carers of OPMHN. Some homes also offer day care for those who find it difficult to cope alone but return home at night. This type of provision has a role to play both in providing emergency respite but also regular breaks. If the support of carers through respite provision is to increase this is one option to be considered further. It was a common opinion that more respite care was needed both in terms of the amount of provision but also in terms of diversity of provision and flexibility and that it was an essential service to sustain carers and enable them to care for longer. Wherever the respite care is provided care staff need to be professional and trained to meet the needs of OPMHN, learning sensitive communication skills and strategies to cope with particular behaviours. Carers need reassurance that their relative is somewhere that can meet individual needs in a sympathetic and appropriate way, providing where possible a substitute for normal routines. Respite can also provide activities and stimulation. This can be built into the routine of visiting the respite service and has the scope to involve volunteers matched to individuals with similar interests.

Recommendation: SSD should extend and encourage further provision of the range of respite care provided in a variety of settings.

7.18 Day care

Day care services are a vital support network for many carers and OPMHN. These are provided in Kent through the OPDSU, Day hospitals and partnerships with the voluntary sector, such as Age Concern and Help the Aged, and offer a mix of reablement therapy and social therapy.

7.19 Carer's have a very demanding caring role both physically and emotionally, and have access to limited availability of support so every opportunity is vital. Day care requires an older person to be both willing to attend and prepared to leave their home. One carer advised members that carers need the invaluable support of day care provision and that the refusal of their relative with dementia to accept services had led to additional pressures. The alternative was respite care at home, perhaps provided by Crossroads, a voluntary organisation that provides home respite for carers, but this to is limited by availability. On access to day care for OPMHN Maidstone Carers advised Members that although there was a fair amount of day centre places most did not offer these to people with dementia. In general there are not enough day care services for OPMHN across the county. The Health Authority also ran therapy based day care provision but once dementia progressed and the person could no longer take part in the group activities or discussions this service

was withdrawn as it was seen to provide limited benefit. This did not take account of the respite this provided. There is a need for day care provision that is appropriate and structured to meet the needs of OPMHN, particularly dementia. The Committee heard that services are just beginning to understand what is needed in the community for OPMHN. It was also pointed out that there was a gap in provision for younger people with dementia and that perhaps as services develop they should be less age specific. In addition studies have shown that Christmas was often the time carers felt unable to carry on caring as day care services were often closed or there was a reduction in services.¹⁰⁸

7.20 Day Centres play a vital role in reducing social isolation but also play a part in helping older people including OPMHN to maintain skills. The Head of OPDSU informed members that elderly people were often referred to day care services without any activities being identified. Clients need to arrive at day care with outcomes to aim for or work areas already identified.

In day centres, and infact all settings where a person with dementia is cared 7.21 for therapy treatments play an important part in their care. These include 'reality orientation' to gently orientate the person with dementia as long term memory is normally preserved longer than short term memory. 'Reminiscence therapy' which uses triggers, including photographs, objects, dresses, toys and smells, to encourage recall on topics of interest to the person with dementia. By understanding the person, both nurses and carers can use this therapy to stimulate communication, raising the persons self esteem. 'Validation therapy' recognises an individual's feelings by accepting their perception of the truth. For example if someone with dementia says they want to see someone, using validation therapy the nurse or carer would not say someone is dead but ask them to tell you about them, what they were like and gently let them remember. The care staff in both respite and day care need skills appropriate to that setting, putting therapy techniques into practice. "Not Forgotten " states that often Day Care staff do not have adequate training to offer effective care to OPMHN, mostly due to under-investment. In addition to encouraging more day care provision for OPMHN, the development of these skills should be encouraged for all carers and staff working with older people with dementia. These therapies and skills are an effective part of memory clinics and 'Mind Gyms'.

7.22 The Select Committee met with a social worker on an exchange visit from Boston, USA. In similarity to much of the day care provision in the UK within Boston, USA Day care facilities are normally empty by early afternoon.¹⁰⁹ Services in Boston have been developed to use this free time, transport links and facilities to provide respite for carers in the early evening and has proved a very effective use of resources. The utilisation of resources to provide respite or early evening care services could be an exciting opportunity to investigate. Overall day care provision needs to be better co-ordinated to meet the needs of OPMHN, avoiding duplication.

7.23 Effect on carer of someone going into care

At the time a relative is admitted to residential care, carers often feel guilt, relief and anxiety. While caring, carers often lose their social life and social network. Carers

¹⁰⁸ Royal College of Nursing, The pressures felt by informal carers of people with dementia Jan/vol15/no17/2001.

¹⁰⁹ KCC, Notes of meeting between a social worker from Boston and group of the Select Committee, 16/05/2003

also need to know that their relative is well cared for. Armstrong advises that staff should give the opportunity for carers to remain involved and acknowledge the carers expert knowledge of the person being cared for. As discussed in Chapter 5 carers told the Select Committee that people with dementia should be treated as individuals not as clones. Both providers and carers informed members of the importance of understanding the person with dementia, about their likes and dislikes, their background. Armstrong (2000) suggested carers made a 'life story book' that could be shared with formal carers and nurses. This could encourage the person to be seen as an individual and be used to help with reminiscence and validation therapy within the care home.

7.24 Carers reported to the Committee that the process of selecting a care home that was appropriate was quite distressing and intimidating, with limited or no advice or support available from SSD on particular care homes and having to choose from area lists.

7.25 JRF emphasised that best practice should involve relatives as well as residents with dementia in influencing care and the management of the home.¹¹⁰ A further study found that very few family caregivers were involved or encouraged to be involved in the care of someone in a care home setting.¹¹¹ Informal carers based in Kent informed the Committee that there was a lack of opportunity for the carer to contribute to the care plan of their relative now being cared for in a residential care home. They stated that if you have been the main carer for several years you want the opportunity to be involved, and not excluded from caring and made to feel that someone is no longer of your concern. Concern was also expressed that there was a lack of regular information requested (weight levels etc). It is important to recognise that not all carers will want the same level of involvement but that the opportunity should be available. In contrast the OPDSU involved family carers in the care plan process and review. It was highlighted that sometimes due to resource pressures staff relied on prescriptive solutions, so involving carers in decisions ensured a more focused individual response.

Recommendation: SSD need to encourage residential care home providers to involve residents with dementia and their relatives/informal carers in the care practice and the management of residential care homes.

Recommendation: SSD should encourage the involvement of relatives of OPMHN in care role in ways that are appropriate to the needs and circumstances of individual residents and their families.

7.26 <u>Titles of Carers</u>

Evidence has shown that many carers caring for older people request little or receive no support.¹¹² Maidstone Carers told the Committee that carers often did not see themselves as carers but for example as a wife, husband or daughter and do not

¹¹⁰ Joseph Rowntree Foundation, Put yourself in my place – designing and managing care homes for people with dementia, Cantley and Wilson, March 2002

¹¹¹ Joseph Rowntree Foundation, Wright F, The effect on carers of a frail older person's admission to a care home, April 1998

¹¹² Royal Commission on Long Term care, With Respect to Old Age: Long Term Care – Rights and Responsibilities, March 1999

request help. This often meant a long time before they accessed the appropriate support, service or benefits. The importance of encouraging the recognition and identification of carers was acknowledged. The use of the term 'carer' by professionals and many in SSD was however confusing and encouraged carers to believe that a carer is someone who does a paid job and therefore they often did not see information applying to them. There is a need to ensure that definitions and terminology are consistent.

CHAPTER 8: SHELTERED HOUSING & EXTRA CARE SHELTERED HOUSING (ECSH)

8.1 The Royal Commission on the Funding of Long-Term Care (1999) concluded that there was a need to expand alternatives to residential care, including innovative housing scheme development. The change in national policy from providing care to the promotion of independence through prevention and rehabilitation emphasises the importance of 'very sheltered housing' in community care provision. One in ten people aged over 65 live in sheltered or very sheltered housing offers increased security, privacy, choice, communal facilities and a scheme manager. Extra care sheltered housing offers an alternative way of providing housing and care for older people preferring not to enter residential care where ordinary housing no longer meets their needs. 'Extra care' provision is in an emerging market that is relatively immature compared to either residential care or sheltered housing. The government has announced plans to expand extra care housing with 50% more extra care places by 2006, an increase of 6,900 places. Extra care housing can

- provide an alternative to long term residential care
- enable housing services to become better integrated in planning and commissioning of services for older people
- use underused sheltered housing with the right care and support in place
- ones 'own front door' unlike residential care, and the "right to choose and refuse"
- with the right technology in place offer a real alternative for OPMHN
- play a part in rehabilitation and intermediate care of OPMHN and older people

8.2 The key differences of enhanced/extra care sheltered housing to residential care are residents tend to have a higher disposable income, greater independence, choice and control over their own lives and relatives have greater involvement offering care and support rather than just visiting. It is also viewed as a place to continue living in not die in. There are however several issues in sheltered housing provision in relation to premises, staffing and care provided.

8.3 Extra Care Sheltered Housing In Kent

The Kent "Sheltered Housing Strategy" is focused on achieving the Next Four Years target to provide an additional 1000 sheltered housing units in Kent and the PSA target to reduce admission to residential care. The strategy identified a serious shortfall of extra care sheltered housing for older people across Kent and increasing demand due to demographic pressure. It states that 25% of people admitted into residential care could be more appropriately accommodated in extra care sheltered housing. It is estimated that between January 2001 – January 2002, 324 people could have entered ECSH if it had been available rather than residential care. For an older person entering extra care sheltered housing rather than residential care SSD estimate the annual savings are £9,360 per client (May 2003).

Recommendation: The Sheltered Housing Strategy and its recommendations should be endorsed, supported and encouraged.

8.4 Provision of ECSH is infrequent and limited. Within Kent several areas are identified that need further development of extra care sheltered housing. These are

- Ashford *
- Canterbury (possibly)
- Dartford
- Dover (possibly)*
- Gravesham
- Maidstone

- Shepway
- Swale
- Tonbridge and Malling*
- Tunbridge Wells
- * augmentation of services

(At the time SSD collected information Sevenoaks and Thanet had not identified a development need for ECSH and will review services that are currently delivered.)

8.5 Extra Care Sheltered Housing for OPMHN

Historically the majority of sheltered housing and ECSH provision has been in the social housing sector and health strategies did not recognise the role of housing. Now the role of sheltered and extra care sheltered housing is becoming increasingly understood, recognising the need for housing alternatives to residential care to address the needs of older people with mental health needs and that housing is a key resource. Through joint planning with Health gaps in provision have been identified, including supporting people with dementia and intermediate care for people otherwise in acute beds. The incidence of dementia in sheltered housing is increasing partly because people are entering sheltered housing at a later age when they are physically and mentally frailer. Research concludes that sheltered housing "has been found to be a successful environment in which those with dementia can live with well being".¹¹³ These schemes can meet the needs of OPMHN, particularly within the right building, with the right services and with the right staff.

8.6 <u>Scheme managers/ scheme wardens and staff issues</u>

For older people with mental health needs the feeling of safety is an important factor. In an ECSH environment this is often provided by the availability of a scheme manager or warden. The role of the scheme manager/warden is changing and future developments in ECSH will influence this further. Scheme wardens can be either residential to a particular scheme or be a 'floating service', supporting several local schemes. This has developed where people have refused the traditional service, opting out of the daily contact by the scheme manager. The scheme manager then only supports those who need or request support. Despite opting out of this service, service charges remain the same. To understand the scale of this issue it would be necessary to undertake a survey and analysis to find out how many services were being paid for but not used so that adjustments could be made. It is unclear at this stage which service is preferable and would need to be informed by a cost analysis and user preference. There was no common agreement amongst providers to withdraw residential scheme managers and replace them with floating support. Some providers recruited 'visiting or office hour' managers. The reasons for this were due to difficulties in recruitment and cost effectiveness.

¹¹³ Kitwwood, Buckland and Petre, Brighter Futures (1995) as cited in McDonald and Curtis, Not Alone: A good practice guide to working with people with dementia in Sheltered Housing, Anchor Trust, 2001

8.7 To provide effective support providers stated that scheme wardens/managers needed training in awareness and issues relating to dementia. Training tended to be adhoc rather than a planned programme of opportunities to share training. The three main resources needed are staff with specialist knowledge to lead the training sessions, venues to hold the training in and catering. A joint training initiative could help strengthen links across the agencies, share expertise and the costs, with agencies contributing the various resources needed.

8.8 There is concern that as residents become more dependent a scheme wardens' time is increasingly taken up by the more dependent clients. Schemes therefore can only support a certain number of highly dependent clients without impacting on other residents. The aim is to achieve a mix of need levels at any one time. If a client develops dementia whilst in sheltered housing this would be discussed with the resident, their family and social services as to how needs can be met. Ideally someone would be maintained at home for as long as possible. Extra care sheltered housing can meet these changing needs without requiring the traumatic relocation of a resident until such time that the dementia has progressed to a stage where needs of the individual can no longer be met. It was argued that better co-ordination between social services and housing would lead to improved services for OPMHN.

8.9 Kent providers found that the introduction of residents with mental health needs into a sheltered housing or ECSH setting faced similar issues as within care homes. Some residents did not react well to being amongst residents with mental health needs as they did not like to see what their future might be. Residents were more readily accepted if dementia developed whilst in the setting rather than transferring in after the onset of the illness. Providers stated they worked with individuals to overcome this as OPMHN needed to be accepted socially by other tenants for a scheme to successfully meet OPMHN needs.

8.10 Social Isolation

Social isolation is a key factor in admission to residential care. Extra care sheltered housing provides opportunities for social interaction and the individual a choice about their own lifestyle. West Kent Housing Association (WKHA) highlighted that tenants could for instance cook together or for themselves and choose whether to join in or organise activities. ECSH can be communal in emphasis. As with residential care it was noted that an important element of care and social interaction was to maintain or build links with the local community. Two good examples from WKHA are the participation in the 'Swanley in Bloom' competition, which raised the profile of the scheme but also increased interaction with the community. Another innovative scheme established a partnership between residents, a special needs school and the Groundwork Trust to develop a sensory garden. This proved a great success and very rewarding to both children and older people working together. If posts are created to look at social interaction within residential care, perhaps they could also promote community interaction in sheltered and extra care sheltered housing. The success of the schemes was due to the commitment of the teams. Through the promotion of the benefits and good practice examples, similar initiatives could be encouraged across Kent, building upon local partnerships and forging new links.

8.11 The introduction of PC's has also enabled residents to write to friends and family, send or receive email letters and shop online. Again this is optional but provides choice and is not intended to replace visiting local shops but enhance opportunities. The volunteer bureau supported this, teaching basic IT skills.

8.12 There was a common opinion that developments in technology offered many benefits at a relatively small cost, and could be moved between buildings to support individuals as needed. There is an opportunity to use technology to support OPMHN live independently and increase confidence in doing so. This is discussed further in Chapter 9.

8.13 <u>Rebuild, refurbish or modernise buildings</u>

A large proportion of the sheltered housing stock is unsuitable to meet current expectations, with high numbers of bedsits and limited or no disability access.¹¹⁴ The expectations of older people in sheltered housing are changing, for example the majority would like two bedrooms so that visitors or grandchildren can stay and people are increasingly home owners and want to retain their own household goods, furniture and memories. ECSH therefore needs to be self contained and of a reasonable size. The Committee heard that Kent sheltered housing building stock is often unable to meet current expectations or meet needs of older people. The decision to either refurbish or rebuild is influenced by the building, land and resources available. It was felt that although the option to demolish and rebuild was a 'radical solution' it was sometimes more cost effective than remodelling. Refurbishment of sheltered housing is necessary particularly to upgrade to very sheltered housing. In parallel to this is the need to consider how to house current residents during refurbishment and if the scheme changes to provide ECSH. Landlords of traditional sheltered housing, especially where this is difficult to let, are remodelling these to make it capable of housing higher levels of care services. Before schemes are remodelled consideration should also be given as to whether care packages could be increased within the current structures, and lessons learnt in building enhanced care units could be transferred to inform building of standard units. Older people could also be involved in developing schemes as in construction partnership arrangements involving all stakeholders including Occupational Therapists and end users in the construction design process.

8.14 As there is often a cash resource issue for developing schemes and a need to balance sentiment and future need KCC are encouraging all the relevant stakeholders to work jointly and take a more strategic overview.

8.15 Image and Difficult to let units

There was consensus that some sheltered housing units throughout Kent were difficult to let, but predominantly in East Kent. A combination of factors contributes to this including undesirable location, the size of units (bedsits) and lack of amenities and facilities. The availability of transport and distance to shops is also an issue. There is also greater emphasis on support provided at home so older people do not need to move into sheltered schemes but may find ECSH more appropriate. A further reason is the lasting image of being 'a public provision'. It was also reported that it

¹¹⁴ KCC, Report to Cabinet: Sheltered Housing strategy, 12 May 2003

was unclear how people know a scheme is available. Many relied on word of mouth and subsequently resulted in some older people entering residential care unaware of schemes locally. 'Rectory Close, Snodland' was cited as a good example as this did not appear to have an image problem. There are a mixture of unit types from 1 to 2 beds to bungalows, the site is attractive, has mixed use to meet mixed needs and the possibility to progress in the scheme as needs change but retain familiar contacts.

8.16 Refurbishment and redecoration can solve some of the issues. Marketing also has a part to play. Private schemes are high profile and supported by attractive glossy flyers or magazines inviting people in and advertising the benefits of the homes. Stakeholders agreed that raising the profile of sheltered housing and extra care housing was needed.

Recommendation: SSD (in partnership) should raise the profile and improve the image of sheltered housing and extra care sheltered housing.

8.17 <u>Support schemes</u>

The Supporting People Programme (SPP) aims to plan and improve housing related support services, and prevent crises such as hospitalisation and institutional care, by providing early support when it is most effective. The SPP provides funding for 'support services' delivered to a range of people across all housing tenures, including OPMHN and sheltered housing or extra care sheltered housing. This introduced the Supporting People Grant, which is administered locally rather than through the Housing Benefit as before and is paid direct to the provider not the client, is supported by partnerships with housing, social services and health. The care provided in sheltered housing and ECSH will be regulated under the Care Standards Act 2000. Flexibility of service is important so older people can proceed through the service as their level of need increases, maybe supported by cluster care arrangements.

8.18 "Active care - active lives" gives KCC's commitment to ensure support to enable older people to stay in their own home or community. Through the Supporting People partnership KCC will share expertise and additional resources to influence strategic housing issues. The document states that KCC will achieve this by

- promoting designed in adaptability
- planing holistically for housing and support
- develop best practice e.g. very sheltered housing
- develop the concept of retirement communities

8.19 The supporting people programme will monitor basic housing related support such as warden support and community alarm services. KCC will achieve this by 'maximising the opportunities of Supporting People partnership to address housing and housing-with support for older people in Kent; providing advice ... on claiming the benefits to which they are entitled'.

8.20 Communal living provides possible economies of scale and are ideal for 'cluster care' arrangements for care staff, reducing travelling time and enabling residents to take their time through a staggered visit. Cluster care arrangements

have been used successfully by West Kent Housing Association providing domicilairy care to tenants in extra care sheltered housing. Concern was raised that costs of support schemes within ECSH and sheltered housing varied significantly for the same service in different areas of the county and that the Supporting People Team had recognised the need to investigate this.

8.21 <u>Owner-Occupiers</u>

Sheltered housing provides an alternative to residential care. Traditionally this type of housing has been in the public sector with limited opportunities for owner-occupiers. In 1997 only 9% of sheltered housing units were provided by the private sector and aimed at the upper end of the market.¹¹⁵ Owner-occupiers also need access to this type of provision to give them options other than residential care. Canterbury City Council and WKHA stated that their ECSH properties were all rented and that there were no owner-occupiers. Yet DOH "Quality and choice for older people Housing" says consideration should be given to owner-occupiers.¹¹⁶ Local providers expanded by explaining that older people with assets were not excluded from the process but assets might affect rental/benefits to some degree. Criteria for eligibility varied depending on the Housing Association, the area, local demand, levels of need and may take into account assets and availability of similar ECSH provision privately. Although older people are not excluded on capital grounds, someone with capital would not be the highest priority in comparison to a person with greater need or someone freeing up a council house for a family. There is a need to consider in developing new schemes the integration with the private providers/developers perhaps through split tenure or mixed tenure schemes (none available locally).

Recommendation: SSD should encourage the provision of sheltered housing options accessible to owner-occupiers (and owner-occupiers with MHN) and encourage the involvement of private sector/developers and the development of split tenure or mixed tenure sites to meet local needs.

8.22 Rural area provision of Sheltered Housing

Often those living in rural areas want to enter sheltered housing type provision situated in local rural area, but most private sheltered housing is in urban area as can be difficult to gain building permission on green belt for optimum number of units (50). Unclear how big an issue this is. Also many shops in the rural areas are closing which will limit independence of some residents who will need to rely on shops delivering, friends or possibly internet shopping. Although many shops are happy to set up a delivery scheme being active is a critical part of maintaining independence.

8.23 Fire safety

It is estimated that 3.1 million people live in 760,000 houses in multiple occupation (HMOs), many of whom are elderly. Fire statistics show 34.8% of all fire deaths and 39.2% of all fire injuries occur in HMO's, equating to 227 people dying and 6, 240 injuries. It is argued that the most vulnerable are housed in the highest risk

¹¹⁵ Tinker et al 1999,Alternative Models of care for older people, The Royal Commission on Long Term Care with respect to old age: Long Term Care - Rights and responsibilities research volume 2 (1999)

¹¹⁶ Department of Health, Quality and Choice for Older People's Housing – a strategic framework, January 2001

properties.¹¹⁷ Although fire alarms give warning to evacuate, the fire still often guts the building or room. The use of sprinkler systems in multi occupancy homes could help reduce deaths and injuries caused by fire and gain extra time to vacate the premises or rescue. Installation is generally around £1/sq ft.

8.24 In response to the 'Next Four Years' target to 'work with the Fire Brigade to reduce death and injury from accidental fires in dwellings, and to fit smoke alarms in properties identified at risk'. Adult Services plan to take action by taking account of fire precautions in drawing up contracts with residential and nursing homes, and encourage that fire regulations are integral to the inspection process of the NCSC. Plans to refurbish or rebuild sheltered housing or ECSH should consider looking at including sprinkler systems.

Recommendation: SSD need the involvement of the fire brigade in new build development of sheltered housing schemes as part of the emerging joint initiatives.

8.25 Planning and Development

KCC are working to build strategic links to plan for the housing and care needs of older people. Joint discussions between Kent County Council, district councils, housing associations, the health services and private and voluntary groups has led to the establishment of working groups to improve services for older people. This is a welcome step and should be encouraged. The working groups aim to develop a shared vision to provide choice and independence, pooled budgets, more housing options, greater use of home improvement schemes and care and support in the home.

8.26 The private sector in Kent has raised concern regarding the difficulty to find land and obtain the necessary planning permissions for sheltered housing. Large amounts of land has been acquired for development profit which excludes developing for the middle to lower end of the market as the level of service charges may be restrictive in private developments.

8.27 Kent County Council are referred to as the "strategic enabler". KCC also has the opportunity to contribute land at less than 'best value' where this would promote or improve social well-being and the discount value does not exceed £2million. KCC could therefore contribute land as part of a scheme to develop extra care sheltered housing, despite conflicting aims to raise capital by selling land at best possible price. There is a need to look strategically and establish links with the capital receipts review team, and focus on "best value of provision not maximising value from sale of land".

Recommendation: The contribution of land from KCC for appropriate schemes should be encouraged and SSD and the Property Group capital receipts team should be proactive to ensure identification of potential sites.

8.28 Development of area boards could give opportunity to look at some of these issues. It was noted that there are large-scale private sector housing developments

¹¹⁷ Residential Sprinkler Association, Campaign for Fire sprinklers in HMOs, 2003

in Kent (e.g. Ashford and Thames Gateway) that could be encouraged to include some provision for older people and extra care housing. Lots of flats have or are being developed in Maidstone but few with lifts that would help older people, young families and disabled. Foyer charging points could also be useful inclusions.

Recommendation: SSD should use influence to encourage developers/planners to include lifts in two/three floored schemes and encourage 'building for life - building for all' principles.

8.29 The DOH has £690 million for private finance initiatives over the next two years. KCC are keen to be proactive and are developing PFI bids in partnership with the relevant stakeholders to develop a number of ECSH schemes across the county for OPMHN and people with learning disabilities. A bid was being drawn up for submission in September 2003 for £40 million credits. The preparation of bids is expensive in time and resources. The PFI team could contribute their experience and project management capacity to pull bids together across Kent district councils, therefore achieving economies of scale and a more strategic approach to developing extra care sheltered housing bids. The needs of OPMHN and housing also need to be balanced with other strategic priorities (learning disabilities and homeless) and could form part of a joint structure plan.

8.30 Care Communities

KCC aim to develop the concept of retirement communities in Kent over the next ten years. 'Hartrigg Oaks' opened in 1998 and is the first Continuing Care Retirement Community in the UK. It provides high quality accommodation and communal facilities, alongside extensive care and support services. Services are funded by capital payments and pooling of residents' annual fees to create a shared resource. This option gave residents

- a housing solution that supported their independence
- security
- peace of mind with availability of onsite care services.
- spacious accommodation (bungalows)
- onsite facilities (library, arts and crafts room, fitness suite), active social life and community atmosphere
- fixed fee for services (except for inflation) even if admitted to onsite care home

(Source: JRF, Residents views of a continuing care retirement community, Sept 2003)

8.31 However there were issues around some of the design features of the bungalows and the onsite management of dementia type illnesses. The scheme needs to achieve a balance between those who need care and support and those who don't and therefore aims to attract 'young-old'. Services provided are home help, personal care and 'pop in'. These services are not specifically geared to meet the needs of OPMHN but it could offer a feasible alternative if the right support services were in place or those currently available could be developed to meet these needs.

8.32 There was mixed response from witnesses to the idea of care communities and a concern that these would need to consider actively involving and being part of the wider community. This is supported by residents at Hartrigg Oaks who expressed most satisfaction for those who led active lives both within and outside Hartrigg Oaks.¹¹⁸ It is estimated that a retirement village of 200 units is needed to contain development costs for middle market purchasers.¹¹⁹ In conclusion JRF state that although social rented or shared ownership schemes for older people are unlikely to use the same funding model as Hartrigg Oaks, social landlords can learn from the way care, accommodation, amenities, resident led activities and general site operation were provided.

¹¹⁸ Joseph Rowntree Foundation, Residents views of a Continuing Care Retirement Community, September 2003 ¹¹⁹ Laing and Buisson (2001) Care of elderly people: market survey 2001 14th edition, as cited in Darton and Netton, What potential is there for replacing residential care provision with other assisted living options?, 2003

CHAPTER 9: ASSISTIVE TECHNOLOGY

9.1 The use of technology to support independent living for older people is mentioned in many government policy documents and has an important role in developing better support for carers. Rising demographic pressures, attention to costs and efficient alternatives to traditional labour intensive care support mean that technology needs to be given consideration to enhance existing provision. There is a broad range of information and communication technology that can promote the independence of older people and older people with mental health needs. This chapter considers how this, in conjunction with assistive technology, can be used to support OPMHN to live safely and independently in residential care homes, in their own homes and alternative care settings. The following definitions are commonly agreed upon:

- <u>Assistive technology</u>: equipment or systems that can assist people who have difficulties, due to age, in carrying out every day activities.
- <u>Telecare</u>: care provided at a distance using information/communication technology, generally to people in their own homes
- <u>Smart Homes</u>: homes in which technology has been installed to help control a variety of functions and provide communication with the outside world.

(Source: Curry, Trejo Tinoco, Wardle October 2002)¹²⁰

9.2 <u>The Policy Context</u>

As discussed in Chapter 3 Government policies for older people aim to promote independence, provide person centred services, help people to live in the community for as long as possible, integrate services and support carers. The use of technology to help older people and OPMHN live at home is in line with government policy aims.

9.3 "Information for Health" ¹²¹ acknowledged that " telecare technology will be used to provide reliable but unobtrusive supervision of vulnerable people who want to sustain an independent life in their own home". In addition the national strategic programme for IT in the NHS ¹²² included the development of telecare and monitoring services; and the Royal Commission on Long term Care recognised the importance of housing adaptations and the potential contribution of future developments in assistive technology.

9.4 The *NHS Plan* ¹²³ outlined the development of services for older people to minimise admissions to residential care and hospital, support early discharge, and reduce bed blocking. It included the expansion and modernisation of community equipment services, such as grab rails to fall alarms and remote sensor devices. The National Service Framework also endorsed the wider application of new technologies to support older people.

¹²⁰ Curry, Trejo Tinoco, Wardle, The use of information and communication technology to support independent living for older and disabled people, October 2002

¹²¹ NHS Executive, Information for health-An information strategy for the modern NHS 1998-2005, 1998

¹²² Department of Health, Delivering 21st IT support for the NHS, 2002

¹²³ Department of Health, The NHS Plan,, 2000

9.5 "Quality and Choice for Older People's Housing – A strategic Framework" ¹²⁴ recognised that although some older people will want to live in for example Sheltered Housing or care homes, it reaffirmed that

"housing, care and support policies need to focus on enabling older people to live as part of the community in their own homes... for as long as they wish to do so."

It endorses the use of technologies such as telecare and Smart homes to enable older people to live safely at home and widen the housing options available to them. The Supporting People guidance also supports the use of technologies and the opportunities they offer to provide "cost effective and high quality support".¹²⁵

9.6 The 2002 *Delayed Discharges* ¹²⁶ report emphasised the potential usefulness of telecare. It stated that telecare has a "major contribution to make as part of the strategy for developing alternatives to hospitalisation...achieve cost savings... be a key component...to allow people the choice of staying longer in their own homes".

9.7 Assistive Technology in Community Equipment Services

Assistive technology as defined earlier provides equipment or systems that can assist older people in carrying out every day activities. These can include simple care equipment and adaptations such as grab rails and bath seats, expanding to more sophisticated equipment such as environmental controls, fall alarms and remote sensors. This definition therefore includes telecare services. Government policy states that the use of 'assistive technology' should be an integral part of an assessment and be considered when a care package is developed. The Integrating Community Equipment Services (ICES)¹²⁷ programme, supported by a national implementation team, will

- lead to the provision of integrated community equipment services by 2004
- improve the range of equipment on offer and the number of people who benefit
- increase efficiency by modernising purchasing, supply and recall
- extend the use of new telecare technologies to support, for example OPMHN

9.8 *"Fully equipped 2002"* reported progress in improving ICES as uneven.¹²⁸ These assistive technology services are an important element of strategies to promote independence. The National Service Framework for older people states that effective provision is likely to slow down deterioration, prevent falls and protect health of users and carers and endorsed the wider use of technologies to support the safety and security of older people. Occupational therapists play a key role in the assessment of individuals and use of assistive technology to help maintain independence. (The Community Equipment Services were discussed further in Chapter 6.)

¹²⁴ Department of the Environment, transport and regions, Quality and Choice for Older People's Housing – A strategic Framework, The Stationary Office 2001

 ¹²⁵ Department of the Environment, Transport and the regions, Supporting People –Policy into practice, 2001
 ¹²⁶ House of Commons Health Committee, Delayed Discharges, 2002

¹²⁷ Department of Health, Guide to integrating Community Equipment services, 2001

¹²⁸ Audit commission, Fully Equipped: Assisting Independence, 2002

9.9 <u>Community Alarm Services and Telecare</u>

Community Alarm Services provide a service in response to an alarm triggered by users, and have been used in the UK for sometime. Curry et al (2002) report that there are over 300 services serving more than 1 million people. Alarms are linked to a call-centre and are activated by the user if assistance is needed, for example after a fall. The call centre then initiates a response, perhaps from informal carers or mobile staff as necessary. These services can be further developed by installing telecare, such as passive alarms and sensors which alert the centre when hazards occur.¹²⁹

9.10 Telecare can enable older people with mental health needs to remain at home by reducing risks and reassuring users and carers, and falls within the remit of ICES. Curry et al state that telecare can be used to provide information, reminders, reduce social isolation, and support rehabilitation and intermediate care. Telecare includes

- sensors that can detect falls, wandering, hazards such as fire or gas, and trigger a human response or switch off equipment
- electronic prompts or memory aids
- video conferencing and specialised telephones

(Source: Curry, Trejo Tinoco, Wardle, October 2002)

9.11 Telecare can be used to either alert resident staff or resident informal carers; or go off-site to a community alarms service. There are several large-scale telecare demonstration projects, which are intended to develop into mainstream service. The 'Safe at home' project, led by Northamptonshire County Council (NCC) Social Care and Health Directorate, was established to explore the use of assistive technologies to meet the needs of older people with dementia remaining in their own homes, and to support their carers in conjunction with home-care services. It applied some of the findings of the ASTRID guide to use technology within dementia care.¹³⁰ ¹³¹ ¹³² The project uses calendar clocks to help with time orientation, alerts for resident carers and devices linked to an alarm service e.g. gas detectors which temporarily disconnects the supply and alerts a response. Curry et al (2002) reported that in

"comparison with a matched group of people with dementia who did not use technology, 'Safe at Home' users tended to remain longer on average in their own homes. The scheme apperared to be very cost effective: community care package costs for Safe at home users rose less quickly than for the comparator group, and the costs of hospital, nursing, and residential care for the comparator group were significantly higher".

The NCC intention is to expand the 'Safe at Home' project into a county-wide service.

¹²⁹ Curry, Trejo Tinoco, Wardle, The use of information and communication technology to support independent living for older and disabled people, October 2002

¹³⁰ Curry, Trejo Tinoco, Wardle, The use of information and communication technology to support independent living for older and disabled people, October 2002

¹³¹ Frisby and Price, ASTRID: A social and Technological Response to the needs of individuals with Dementia and their carers, September 2000

¹³² Tunstall, Glossy brochure, Northampton – safe at home project :Dementia, 2003.

9.12 Telecare technology in Kent has a considerable part to play in assisting older people to remain at home, limiting some elements of 'fear of harm' that often contribute to entry into long term residential care. In Kent widespread take up of home based telecare has been limited. The use of telecare linked to a call centre (24/7) has the potential of supporting independent living in the community for large numbers including OPMHN, assisting early discharge and reducing admission to residential care homes. The current service is triggered by push buttons rather than linked sensors. Historically community alarm services have been mainly provided by Housing Associations. For telecare to develop successful pilots and later into mainstream services that contribute to housing-based alternatives to traditional residential care for OPMHN, it will require partnerships between social services, health, housing, community alarm services and the private sector. The call centre could direct staff to problems arising and could link to enhance current provision and utilise existing resources (appropriately resourced care homes).

9.13 Telecare should also be considered within the context of Sheltered or Extra Care Housing and the various residential care home settings. The Kent Older People Direct Services Unit stated that Telecare is an option they would like to consider for the future e.g. wander monitors, moisture detectors so staff could assist clients without unnecessary disturbance to others and acknowledged the benefits these offered. The successful delivery of telecare to the home, residential care home or Extra Care / Sheltered Housing is dependent on both the condition of the building and the ability of the care provider to meet service user needs. There was not a clear understanding of the precise cost implications for expanding the use of technologies to particular client groups although it was thought to be relatively expensive.

9.14 Key issues raised with the Select Committee by witnesses included

- the difficulty to refurbish some buildings to include new technologies
- the need to use modular systems that can be added as need arises e.g. using technology only where they can benefit the person with dementia and are supportive of appropriate care arrangements
- recognising that the new technologies are suitable for some but not for all and the need to listen to individual and carers needs and preferences when proposing technology not just to drive technology forward
- technologies should be used to enhance rather than replace human social contact
- concerns regarding ethical issues surrounding confidentiality and remote analysis of a person's activities
- need to be user friendly, simple and complement existing provision

9.15 Care Homes and Sheltered Housing:

Kent based OPMHN residential care home providers reported that some of the technology could be used effectively to provide high quality care for OPMHN. They highlighted that, passive alarms and/or sensors could for example be used to monitor when a client with dementia was night-time wandering or alert staff to incontinence during the night. This was thought to be particularly useful so clients were not awakened unnecessarily, or night-time staff covered several areas and clients were based over several floor levels in a building. Alerting staff appropriately and enabling them to respond to the need.

9.16 Although the national minimum standards require adequate call systems, they do not encompass the use of new technologies for care or monitoring of older people being cared for. The use of these new technologies (sensors to monitor wandering, moisture sensors) in care homes is limited but could be developed. In Kent this type of service has developed most within the Sheltered Housing and Extra Care Sheltered Housing. Rectory Close is an excellent example of Sheltered Housing with enhanced care support. This scheme uses Invicta Lifeline to assist with the care and support of older people, a community alarm and out of hours service and sleep-in care staff. Future plans include developing services further to ensure the environment is safe and appropriate for people with mental health needs, particularly those with dementia. Rectory Close has installed telecare equipment where tenants have dementia, including flood alerts, wander at night alarms. The alarms are linked to Invicta Lifeline, who filter calls and either route for example to the scheme manager (if on duty) or to carer on site ('sleepover' staff). The telecare service is provided by a private provider who also supports the NCC 'safe at home project'.

9.17 As this is a relatively new service technology, as pilot projects are started and expanded in Kent they will need to be monitored and evaluated on outcomes, highlighting the possible benefits to be gained. Curry et al emphasised that the impact of new technologies on daily staff activities should be assessed. Changing services require a change in staff culture. This is also true with technology. As this type of service develops, care staff will need to be made aware of the new activities, procedures and potential benefits that could be offered to OPMHN. Training will therefore play a vital role. A significant amount of research activity is being undertaken in the UK at the moment on the use of technology to support older people. As the findings are reported they will continue to inform Kent's development of this type of service.

Recommendation: SSD should consider further the use of new technology to support OPMHN within the various care settings and look to develop this area in partnership where appropriate.

9.18 Smart Homes

Smart Homes use electronic network technology to integrate devices and appliances found in most homes. This enables the home environment to be controlled centrally or remotely. The technology can for example open curtains, run a bath, turn on the kettle via a remote button, open windows or doors and potentially assist independent living through motion detectors to gently turn on lights at night if users frequently get up.¹³³ The Joseph Rowntree Foundation (JRF Nov 2000) states that Smart homes technology "offers the prospect of significant improvements in the living standards of older or disabled people who are heavily reliant on home care".¹³⁴ Currently these are generally available at the high price end of the housing market. The JRF findings also state that the benefits can only be a reality if the market develops, improving both availability and affordability of technology. Smart Homes and Telecare use similar technology, and smart homes would probably install the monitoring equipment needed for telecare. Smart sub-systems can provide modular support for specific

¹³³ Joseph Rowntree Foundation (JRF), What the house can d, jrf.org.uk/housingandcare/smarthomes, 2003

¹³⁴ Joseph Rowntree Foundation, Findings: The market potential for Smart Homes, Pragnell, Spence, Moore, Nov 2000

problems e.g. reminders if electrical appliances are left on. Although the features of Smart Homes were acknowledged to have potential, the Select Committee heard reservations regarding the complexity of the systems, technical failure and 'the big brother' effect. This is underpinned by the JRF findings reporting that those uninterested in this technology were likely to be 55+, there was "a lack of common standards, an inappropriately skilled workforce and ... the Smart Home market has yet to develop a sustainable momentum" (JRF Nov 2000).

9.19 <u>Demonstration of technology:</u>

Although there is considerable innovation and development in technology to meet the needs of people with dementia it is often difficult for users and their professional or family carers to find out about the equipment and services available. Both carers and care professionals highlighted the need for adequate areas to demonstrate the type of telecare technologies and specialised equipment available and the services they could provide to assist independent living for OPMHN and older people. 'Disabled Living Centres' could be useful but would be expensive to develop. It was suggested to the Select Committee that the opportunity for a demonstration flat within a sheltered Housing scheme would be really beneficial but was unlikely. The development of an interactive CD was more probable. If a setting was developed this could be part of the Independent Living Centres, rather than at a particular housing scheme. They could also include the demonstration of aids and adaptations and technology found in Smart homes.

9.20 One example of such a scheme, although based only on Smart homes and not telecare is 'the Gloucester Smart House'. The Gloucester Smart House has been converted from a 3-bedroomed house into a dementia friendly environment that demonstrates how new technology can assist people with dementia remain independent for longer e.g. locator boxes. There is monthly open day where tours are given and the technology explained.¹³⁵ The 'safe at home' scheme has also set up a demonstration house so professionals, carers and potential users can test the appropriate technologies. A similar idea could be developed for Kent.

Recommendation: SSD should consider extending the use of technological services to assist the care of OPMHN at home and in sheltered housing.

Recommendation: SSD should provide information for users, carers and professionals on the possibilities of technological services as they are developed across Kent.

Recommendation: SSD to develop a county wide strategy for the use of assistive technology, including telecare in community care provision

9.21 Lifetime Homes

Lifetime homes have key design features that ensure a new house or flat will meet the needs of most households. The design changes are minor additions to the already existing Building regulation requirements for adaptability and flexibility to be

¹³⁵ Dementia Voice, A report on the Gloucester Smart House Project undertaken by Dementia Voice, accessed at www.dementia-voice.org.uk/projects: printed July 2003.

designed into the home. The emphasis is on accessibility to meet a variety of changing needs – families with pushchairs, wheelchair users etc.¹³⁶ Planning and building new homes could also consider design features that would assist older people with mental health needs.

9.22 In conclusion changing services to incorporate technological support will require innovation and forward thinking to meet the community care agenda for an ageing population. The support that is incorporated should not replace face to face care but assist provision and be appropriate to the individuals needs. Some might argue that technological solutions are unlikely to be welcomed by older people yet a BT Anchor Trust project found enthusiastic support for high tech home support systems amongst focus groups of older people. ¹³⁷ (British Telecom 1998)

 ¹³⁶ Joseph Rowntree Foundation, An introduction to Lifetime homes, wwwjrf.org.uk/housingandcare 11/06/03
 ¹³⁷ British Telecom Anchor Housing Trust Telecare Project Briefing Dec 1999 as cited in

APPENDIX I

| Meeting Date | Witness/es Attending | |
|--------------|---|--|
| J | | |
| | Oliver Mills, Pat Huntingford, Martyn Ayre, Michael Thomas Sams | Strategic Briefing – Introduction and overview of Residential care and the alternative models of care for OPMHN |
| 4 July 2003 | David Howells, KCHT | Kent Community Housing Trust, Voluntary Provider |
| | Nadra Ahmed, NCHA + KCHA | Residential Care home Provider, Chairman of National care Homes Association and Kent Care Homes Association |
| | Janice Grant Joanna French | Work of OP/OPMHN Teams (Team Leader/Senior Practioner) |
| | Pam McGregor Chris Belton | Work of District Manager and Head of Adult Services |
| 10 July 2003 | Sharon Matson, Canterbury and Coastal PCT | Work of Head of OP services, PCT |
| | Shaminder Bedi | Cultural Care Issues |
| 17 July 2003 | Stephanie Stanwick, Dartford Gravesham &Swanley PCT | Role of PCT, Domicillary dementia care, recuperative care |
| | Graham Lewis, NCSC Kim Maslyn | National Care Standards Commission in Kent Older People's Direct Services Unit – residential, respite and day care |
| 18 July 2003 | Vic Codling, Alzheimer's Society, | Experience of people with Alzheimer's |
| | Barbara Hagan, Maidstone Carers and 2 carers | Carers experience, voluntary support organisatioin |
| 21 July | David Weiss Christine Collinder | Sheltered Housing, PFI Project |
| | Simon Clark, West Kent Housing Association | Sheltered Housing |
| | Claire Martin Christine Cogdell | Sheltered Housing Intermediate Care/recuperative care/policy |
| | Michael Thomas-Sam Jan Harker | OT Bureau/aids and adaptations/Recuperative Care |
| | Pat Huntingford Elaine Buxton | Domiciliary Care |
| 24 July | Velia Coffey, Canterbury CC Mary Stewart Christine Cogdell | Sheltered Housing Active Care |

APPENDIX II

The four stages or levels of dementia are defined in '*Forget Me Not*' as:

- **Minimal:** where the person has some difficulty in recalling recent events and may mislay or lose things.
- **Mild:** where the person's recent memory is very poor and they are sometimes confused or disorientated.
- **Moderate:** where the person is usually disorientated in time and place, and has difficulty in reasoning or understanding. Sometimes they are incontinent and their emotional control deteriorates.
- Severe: where the person is totally disorientated, unable to communicate in normal speech, may fail to recognise close relatives, and is incontinent and completely dependent on others for personal care. Some people with severe dementia may be aggressive or violent to others. As the dementia progresses, the person can become immobile and totally physically dependent.

There are also different levels of 'need of care', depending on how long an individual can remain alone or independent without needing help.

- Independent: care not needed.
- Long Interval: care needed at least once a week.
- Short Interval: care needed at least once daily.
- **Critical Interval:** care or supervision needed continually or at brief irregular intervals each day.

(Source: Forget Me Not – Mental health services for older people, Audit Commission 2000)

GLOSSARY OF TERMS

ADMIRAL NURSES are specialist dementia nurses, working in the community, with families, carers and supporters of people with dementia.

Dartford and South West Kent Admiral Service, West Kent NHS and Social Care Trust, Darent House, Sevenoaks Hospital, Hospital road, Sevenoaks, Kent, TN13 3PG. Tel: 01732 228246

Maidstone, Medway and Swale Admiral Nurse Service, West Kent NHS and Social Care Trust, Southlands Unit, Rook Lane, Near Bobbing, Sittingbourne, Kent, ME9 8DZ. Tel: 01795 845019

ASSESSMENT (NEEDS ASSESSMENT) The process of defining needs and determining the eligibility for assistance. It is a continuing process which should involve the service user, carers, and all organisations involved in the provision of care for that person.

BED-BLOCKING A bed occupied by a patient who in the consultant's opinion no longer requires the services provided for that bed, but who cannot be discharged or transferred to more suitable accommodation.

BLOCK CONTRACT Is a contract which guarantees a given volume of business for the provider.

CALL-OFF CONTRACTS refer to contracts where a price per hour is specified in advance and paid when a service is provided.

CARE MANAGEMENT A process which involves identifying a person's needs (see assessment), drawing up a care plan and arranging provision of the services required. Services may be purchased from social services, health or the independent (private and voluntary) sector

CARE MANAGER The member of staff (usually, but not always, from Social Services) responsible for assessment,

(Care Manager Continued)

producing a care package and monitoring and adjusting, as necessary, care arrangements.

CARE PACKAGE A combination of services arranged by a Care Manager to meet the needs of an individual.

CART Community Assessment and Rehabilitation Team.

COMMISSIONING The means by which the local authority (and health authority) plan, organise and purchase services for people.

COMMUNITY CARE Services and support to help anyone with care needs to live as independently as possible in their home, wherever that is.

COMMUNITY CARE REFORMS The reforms introduced by the White Paper *Caring for People,* and by the NHS and Community Care Act 1990.

COMPLAINTS PROCEDURE The process which every social services department must have for listening and responding to comments and complaints from users of services.

CONTRACTING The process through which local authorities purchase services from care providers.

COST & VOLUME CONTRACTS refer to contracts that guarantee a block purchase of hours plus a negotiable option to purchase further hours of service.

DEMENTIA Progressive impairment of a person's mental processes, a cluster of signs and symptoms of intellectual and cognitive function being disrupted.

DEPRESSION Feeling low, persistently unhappy, worthless, loss of interest or enjoyment in life, affecting sleep and appetite and stops a person from functioning normally. **DOMICILIARY CARE** Help and services provided in a person's own home to improve their quality of life and enable them to maintain their independence. This can include home care, meals on wheels, and visits by the occupational therapist and/or district nurse.

ELDERLY MENTALLY INFIRM (EMI) Older person(s) with mental frailty e.g. due to dementia.

ELIGIBILITY CRITERIA The 'local authority rules' which determine whether a person is entitled to a particular service e.g. Care Management. The criteria are used so that those with the greatest needs are given priority.

ETHNIC MINORITY COMMUNITIES relates to all sub-groups of the population not indigenous to the UK whose cultural traditions and values derived, at least in part, from their countries of origin.

HOME CARE ls Social Services Department's most extensive service. Since community care, home care has increasingly provided personal care; whilst housework and other domestic tasks have become marginalised. It has also developed into a more intensive at support service targeted more dependent people at risk of admission to residential or nursing care.

INDEPENDENT SECTOR A range of non-statutory organisations involved in social and health care provision, including both private and voluntary/charitable organisations.

INTERMEDIATE CARE is a range of short term rehabilitative services to promote faster recovery from illness, prevent unnecessary acute hospital admission, support timely discharge and maximise independent living. It acts as a bridge between a variety of care settings, includina hospitals, residential and nursing homes, very sheltered housing and people's own homes. Government defines an Intermediate care package as typically lasting no more than 6 weeks.

JOINT COMMISSIONING Where more than one statutory agency join together to commission or purchase new or existing services.

JOINT FUNDING A funding arrangement which includes two or more funders.

KCHA Kent Care Homes Association

KCHT Kent Community Housing Trust

MULTI-DISCIPLINARY (Multi-Agency) the involvement of people from different agencies or professions, combining their specialist skills and knowledge to work towards a common goal.

NCHA National Care Homes Association

NSF National Service Framework

OPMHN older people with mental health needs.

OPDSU Older Peoples Direct Services Unit, Kent County Council.

OTSDU Occupational Therapy and Sensory Disabilities Unit, Kent County Council.

PERSONAL CARE is care which involves support with bathing, washing, dressing, going to the toilet, help with getting in and out of bed, walking and getting up and down stairs.

PRIMARY CARE care provided through the traditional family practitioner services i.e. general practice services, pharmacists, optometrists and dentists.

PRIMARY CARE TRUSTS bring together all the GP practices and their staff in a geographical patch to provide the range of primary care services and to commission other services.

PROVIDERS any person, group or organisation supplying a community care service.

PSSRU Personal Social Services Research Unit.

REFERRAL a request for action may be initiated by an individual or by a professional e.g. their GP.

PUBLIC SERVICE AGREEMENTS (PSA) encourage commitment to achieve targets agreed with local people and partners.

RESPITE CARE may take several forms, e.g. a short stay in residential care or care in the home to give carers a break from their usual caring activities.

SERVICE USER anyone using services provided by Social Services. Other terms frequently used are 'clients', 'customers', 'consumers' or, in the NHS, 'patients'.

SHELTERED HOUSING specially designed housing with varying levels of support, available to rent from district councils or housing associations, or to buy privately.

SOCIAL SERVICES INSPECTORATE (SSI) a section of the Department of Health responsible for monitoring the performance of local authority social services departments.

SSD Social Services Directorate, Kent County Council

STEP-DOWN CARE a way of organising care aimed at freeing up hospital beds by giving patients intensive care at home and phasing this out gradually as their health improves and confidence grows.

STEP-UP CARE increased level of care delivered at home to keep clients out of hospital as long as possible.

TOPSS The National Training Organisation for Personal Social services.

VOLUNTARY SECTOR a range of nonstatutory organisations which include selfhelp groups, consumer forums, umbrella organisations, users and carers groups, lobbying groups as well as organisations providing services for certain groups of people. Voluntary sector organisations may employ volunteers, paid staff or both and are usually controlled by an unpaid (voluntary sector continued)

management committee or trustees. Funding may be received from a variety of sources including grants, donations, fundraising, legacies and sponsorship.

BIBLIOGRAPHY

ADSS, Not Forgotten – Report by multi professional group for better services for people with dementia, accessed at www.adss.org.uk 22/05/03

ADSS, Prevention of dependency in older people: Position of ADSS Older People's Committee, accessed at www.adss.org.uk 16/06/2003

ADSS, Modern Mental Health Services Need Information Support, accessed at www.adss.org.uk 03/04/2003

Age Concern, Response to the DOH consultation on Residential Care, Housing, Care and Support Schemes and Supporting People, June 2002.

Alzheimer's Society, Let's set a fair rate for care Winter 2001/Spring 2002.

Alzheimer's Society, Facts about dementia/What is dementia?, accessed at www.alzheimers.org.uk, 23/04/2003.

Alzheimer's Disease International, The prevalence of dementia, April 1999.

Annual Long Term Care for Older People Conference – A fair price for Care, William Laing 2002

Armstrong, Factors affecting the decision to place a relative with dementia into residential care. Nursing Standard. 14, 16, 33-37, 2000, cited in Royal College of Nursing, The pressures felt by informal carers of people with dementia Jan/vol15/no17/2001.

Armstrong M (Nov 2000) The pressures felt by informal carers of people with dementia, Royal College of Nursing, Nursing Standard Jan/vol.15/no17/2001.

Audit Commission, Forget-me-not – mental health services for older people, 2000.

Audit Commission, Forget-me-not 2002: update – developing mental health services for older people in England, Feb 2002.

Audit Commission, Integrated Services for Older People – building a whole system approach in England, 2002.

Audit Commission, Fully Equipped 2002: Assisting Independence, 2002

Audit Commission, The way to go home, rehabilitation and remedial services for Older people, 2000.

BBC – Health Conditions A-Z, www.bbc.co.uk/health, accessed on 08/09/03

Brownlie 1991, Manthorpe and Hettiaratchy 1993, as cited in McCracken, Boneham, Copeland, Williams, Wilson, Scott, McKibben and Cleave, Prevalence of dementia and depression among elderly people in Black and ethnic minorities, British Journal of Psychiatry (1997) 171. 269-273

Care and Health Magazine, Conversation with Nadra Ahmed, Issue 34 April23 – May 6 2003, 2003.

Community Care Market news, Care Home operators call for more consistency from NCSC, Volume 2 issue 10 May 2003.

Community Care, Councils save cash by capping home care, 7 March 2002.

Community Care, Back Home, Ruth Winchester, 18-24 July 2002.

Crompton J, Ricketts S. A catalyst for change. Driving change in the strategic commissioning of Non-acute Services for Older People, Health and Social Care Change Agent Team, Department of Health, December 2002.

Curry R G, Trejo Tinico M, Wardle D, The use of information and Communication Technology (ICT) to support independent Living for Older People and Disabled People, October 2002.

Dementia Voice, A report on the Gloucester Smart House Project undertaken by Dementia Voice, accessed at www.dementia-voice.org.uk/projects, July 2003.

Dementia Voice, Enable Project - South Cotswold Memory Project -Gloucester Smart House, accessed at www.dementia-voice.org.uk/projects, July 2003.

Dementia Voice, Serving the needs of marginalised groups in dementia care: younger people and minority ethnic elders, accessed at www.dementia-voice.org.uk/projects, July 2003.

Department of the Environment, Transport and the regions, Supporting People–Policy into practice, 2001

Department of Health, A Handbook on the Mental Health of Older People, HMSO 1997, as cited in Audit Commission, Forget me Not, 2000.

Department of Health, Better services for vulnerable people: Executive letter EL (97)62, C1(97) 24, 1997.

Department of Health, Partnership in Action (New opportunities for joint working between Health and Social Services) - A discussion document, September 1998.

Department of Health, Caring about carers –the national strategy for carers, 1998

Department of Health, The governments response to the Royal commission on Long Term care, www.doh.gov.uk, July 2000.

Department of Health, The NHS Plan - A plan for investment, A plan for reform, July 2000.

Department of Health, Guide to integrating Community Equipment services, 2001

Department of Health, Quality and Choice for Older People's Housing – a strategic framework, January 2001.

Department of Health, National Service Framework for Older People, March 2001.

Department of Health, National Minimum Standards for Care Home for Older People, March 2001.

Department of Health, Shifting the balance of power, July 2001.

Department of Health, Press release 9.10.2001

Department of Health, Residential Care, Housing, Care and Support Schemes and Supporting People – a consultation paper, November 2001.

Department of Health, The single assessment process guidance for local implementation and annexes to the guidance, 2002.

Department of Health, Single assessment process Key implications, 2002.

Department of Health, Delivering 21st IT support for the NHS, 2002

Department of Health, The Single Assessment Process Guidance for Local Implementation, January 2002.

Department of Health, The residential care and nursing home sector for older people: An analysis of past trends, current and future demand, 2002

Department of Health, National Minimum Standards for Care Homes for Older People, February 2002.

Department of Health, The residential care and nursing home sector for older people: an analysis of past trends, current and future demand, August 2002.

Department of Health, Improving Older People's services – policy into practice – The second phase of inspections into Older People's services, 2002.

Department of Health, Improving Older People's services – policy into practice – The second phase of inspections into Older People's services. Key messages for service managers and practitioners, October 2002.

Department of Health, Shaping our Future – Championing Change for Older People, London, 27 March 2003.

Department of Health, Criminal Records Bureau Checks on Health and Social Care Staff – A consultation document, 5 June 2003.

Department of Health, Changing places. Report of work of the Health and Social Care Change agent team 2003/2003, July 2003.

Department of Health, Discharge from hospital getting it right for people with dementia, July 2003.

DTLR, Quality and choice for older people's housing, A Strategic Framework, 2001.

Devon County Council, Devon Carers Plan 2001-04, 2001

East Surrey County Council, Joint Carer's Strategy for East Surrey 2003-2006, 2003

Frisby and Price, ASTRID: A social and Technological Response to the needs of individuals with Dementia and their carers, September 2000.

Hofman A, Rocca WA, Breteler MMB, The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings', International Journal of Epidemiology 20, 736-748, 1991, as cited in www.alz.org/dementia / Dementia statistics.

Harvey R, 1998, Young Onset Dementia: Epidemiology, clinical symptons, family burden, support and outcome. NHS Executive (North Thames), as cited in Alzheimer's Society, Younger People with dementia, accessed at www.alzheimer's.org.uk

Help the Aged, Nothing Personal - Rationing Social Care for older people, 2002.

House of Commons Health Committee, Delayed Discharges, 2002

House of Commons, Social Care aspects of the Health and Social Care (Community Health and Standards) Bill, 2 May 2003.

Housing 21, The strategic role of Very Sheltered Housing, 1999.

Joseph Rowntree Foundation, Difficult to let Sheltered Housing, December 1995.

Joseph Rowntree Foundation, The assessment process for older people leaving hospital, July 1996.

Joseph Rowntree Foundation, Integrating user involvement and multi agency working to improve housing for Older People, March 1997.

Joseph Rowntree Foundation, The effect on carers of a frail older person's admission to a care home, April 1998.

Joseph Rowntree Foundation, Press Release. Older People in care homes pay more of their savings than necessary, warns report, 5 May 1998.

Joseph Rowntree Foundation, The importance of 'low level' preventative services to Older People, July 1998.

Joseph Rowntree Foundation, Press Release - Support scheme helps tenants with mental health problems to live independently, 16 September 1998.

Joseph Rowntree Foundation, The role and impact of befriending, October 1998.

Joseph Rowntree Foundation, Press Release. Housing Breakthrough as JRF unveils SMART Home of tomorrow, 16 October 1998.

Joseph Rowntree Foundation, Developing a preventative approach with Older People, June 1999.

Joseph Rowntree Foundation, Meeting the needs of Chinese Older People, September 2000.

Joseph Rowntree Foundation, An overview of the Supporting People Programme, October 2000.

Joseph Rowntree Foundation, Findings: The Market potential for Smart Homes, Pragnell, Spence and Moore, 15 November 2000.

Joseph Rowntree Foundation, Is enhanced Sheltered Housing an effective replacement for residential care for older people?, December 2000.

Joseph Rowntree Foundation, Exploring Ways for staff to consult people with dementia about services, 2001

Joseph Rowntree Foundation, Crossing the housing and care divide, January 2001

Joseph Rowntree Foundation, Piloting choice and control for Older People: An Evaluation, 27 April 2001. Joseph Rowntree Foundation, Communication and consultation: exploring ways for staff to involve people with dementia in developing services, 16 May 2001.

Joseph Rowntree Foundation, Press Release - Pioneering study shows how people with dementia can be consulted about their care, 16 May 2001.

Joseph Rowntree Foundation, Getting older people's views on quality home care services, June 2001.

Joseph Rowntree Foundation, Money well Spent: The effectiveness of housing adaptations, 1 August 2001.

Joseph Rowntree Foundation, The independent care home sector: Implications of care staff shortages on service delivery. The impact of legislative change on the independent, residential care home sector. Stephen O'Kell, 28 January 2002.

Joseph Rowntree Foundation, 'Put yourself in my place' Designing and Managing Care Homes for people with dementia. C Cantley and Robert C Wilson, 12 March 2002.

Joseph Rowntree Foundation, Press release - Care homes for older people 'underfunded by over £1 billion a year'. Calculating a fair price for care: A toolkit for residential and nursing care costs, William Laing, 2002

Joseph Rowntree Foundation (July 2002) The experiences of working carers of older adults

Joseph Rowntree Foundation, Wilcox Steve, Can work – can't buy, Press release – League tables reveal least affordable areas for young homebuyers in the South East, 2003.

Joseph Rowntree Foundation, Residents views of a Continuing Care Retirement Community, September 2003

Joseph Rowntree Foundation, What the house can do, accessed at jrf.org.uk/housingandcare/smarthomes, 2003.

Joseph Rowntree Foundation, Low intensity support: preventing dependency, Foundations 159, accessed at www.jrf.org.uk 29/072003.

Joseph Rowntree Foundation, Introducing Smart Homes, www. jrf.org, 2003

Joseph Rowntree Foundation, Introduction to Lifetime Homes, www.jrf.org, 2003.

Kendall J, The third sector and social care for older people in England: Towards an explanation of its contrasting contributions in residential care, domiciliary care and day care. Civic society working paper 8, 2000 Kent County Council, Active Care – a New Look at Social Care in Kent, 18 Sept 2000.

Kent County Council, Vision for Kent, 2001.

Kent County Council, Better Care – Higher Standards: A Kent Charter for Long Term Care, August 2001.

Kent County Council, The Next Four Years, 2002.

Kent County Council, Kent – The Changing County, 18 November 2002.

Kent County Council, Adult Services Plan: Budget and Business Plan 2003/04, 2003.

Kent County Council, Active Care – Active Lives: A new look at Social Care in Kent, March 2003.

Kent County Council, WK NHS Trust SWK PCT, A proposal for a pilot project for a support at home service for older people with mental health difficulties, March 2003

Kent County Council, Kent County Council Annual Plan, June 2003.

Kent County Council, Cabinet Scrutiny 21 May 2003 Item C1 (C): Sheltered Housing Strategy, May 2003.

Kent County Council, Note of Residential Care meeting with Joan Josser, visiting from Boston USA 16 May 2003-09-30, May 2003.

Kent County Council, SCCHPOC 9 July 2003 Item No B6: KCC Annual Plan and the Next Four Years – main issues in relation to Social Services Targets, July 2003.

Kent County Council, The Island Guide: A Guide to services for older people in Thanet, 2003.

Kings Fund, Future Imperfect – the care and support inquiry, June 2001

Kitwwood, Buckland and Petre, Brighter Futures (1995) as cited in McDonald and Curtis, Not Alone: A good practice guide to working with people with dementia in Sheltered Housing, Anchor Trust, 2001.

Laing and Buisson, Care of elderly people: market survey 2001 14th edition, 2001, as cited in Darton and Netton, What potential is there for replacing residential care provision with other assisted living options?, 2003.

Local Government Association - Housing, Key workers and affordable housing, June 2002

London Health Observatory, Mental Health :Elderly, www.1ho.org.uk, accessed on 08/09/03

Macnair Dr Trisha, Elderly People and depression, www.bbc.co.uk/health/features , accessed 08/09/03

McCracken M, Boneham M, Copeland J, Williams, Wilson, Scott, McKibben and Cleave, prevalence of dementia and depression among elderly people in Black and ethnic minorities, British Journal of Psychiatry (1997) 171. 269-273

McDonald A and Curtis J, Not Alone – a good practice guide to working with people with Dementia in Sheltered Housing, Anchor Trust and The Housing Corporation. ISBN 0 906178 70 3, 2001.

Mittelman M et al. A family intervention to delay nursing home placement of patients with Alzheimer disease. JAMA 1996, Journal of the American Medical Association 276, 21, 1725-1731, accessed at www.minervation.com

The MJ, Fines threat issued over care homes, 14 August 2003.

MIND, Creating Accepting communities – Report of the Mind Inquiry into Social exclusion and mental health problems 1998 –1999, 2002.

NHS Executive, Information for health-An information strategy for the modern NHS 1998-2005, 1998

National Social Services Conference, Choice and Independence for Older People through partnership, 2002.

National Social Services Conference, Smart Houses for Social Support, 2002.

NHS Health Development Agency, The Working Partnership - Book 1:Introduction, 2003.

National Care Homes Association, NCHA responses to government - Care in Crisis? 6 February 2003.

Nolan, Supporting family carers: the key to successful long term care? British Journal of nursing 5, 14, 836, 1996, as cited in Royal College of Nursing, The pressures felt by informal carers of people with dementia Jan/vol15/no17/2001.

OPDM, Preparing Older peoples strategies linking housing to health, social care and other local strategies, Feb 2003.

Office for National statistics, Census 2001: First results: total population by age and gender, 2002.

Powell Jason L, Centre for Social Science, The NHS and the Community Care Act (1990) in the United Kingdom - A critical review, 2001.

PSSRU, Implementing Caring for People, Department of Health, July1994.

PSSRU, Care Homes for Older People Volume 1: Facilities, residents and costs, 2001.

PSSRU, Care Homes for Older People Volume 2: Admissions, needs and outcomes, 2001.

PSSRU, Demand for Long term care for older people in England to 2031, LSE and U of Kent 2001.

PSSRU, Mann A, Schneider J, et al, Depression and the response of Residential Homes to physical health needs, 2001, accessed at www.kent.ac.uk/PSSRU/abstracts

PSSRU, The residential care and nursing home sector for older people: An analysis of past trends, current and future demand, August 2002

PSSRU, What potential is there for replacing Residential Care provision with other assisted Living Options? Discussion Paper. Robin Darton and Ann Netton, March 2003.

Residential Sprinkler Association, Campaign for Fire sprinklers in HMOs, 2003.

Richardson Frank, Latest Developments in the Long Term Care Market, Annual LTC for older people conference, March 2002.

Royal College of Nursing, The pressures felt by informal carers of people with dementia Jan/vol15/no17/2001.

Royal Commission on Long Term Care, With Respect to Old Age: Long Term Care – Rights and Responsibilities, 1999.

Royal Commission on Long Term Care, With Respect to Old Age: Long Term Care – Research volume 2 Alternative Models of Care, 1999.

Royal Commission on Long Term Care, With Respect to Old Age: Long Term Care – Research volume 3 Community Care and Informal Care, Part 2 Policy Options for Informal Carers of Elderly People, 1999.

Scottish Executive, Over the threshold? An exploration of intensive domiciliary support for older people, March 2003.

SPAIN, The underfunding of social care and its consequences for older people, November 2001.

Social Services Inspectorate and Audit Commission, Joint Review of Kent Social services, October 2001.

Thorp S, A model for Building Capacity, Care and Health Issue 35, May 7 – May 20 2003, 2003.

Tinker et al 1999, Alternative Models of care for older people, The Royal Commission on Long Term Care with respect to old age: Long Term Care - Rights and responsibilities research volume 2, 1999.

Tunstall, Glossy Brochure: Northampton – safe at home project :Dementia, 2003.

Wanless D, Securing our future Health: Taking a long term view, HM Treasury 2002.

Warburton and McCracken, With Respect to Old age – Research Volume 3, Ch.2 An evidence-based perspective from the DOH on the impact of the 1993 Reforms on the care of frail elderly people, 1999.

Weightman Gavin, A Real Break – a guidebook for good practice in the provision of short term breaks as a support for care in the community, February 1999.

Which magazine, Care Home crisis, Feb 2003.