

Improving services and support for older people with mental health problems



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Foreword

This Inquiry's first report drew attention to the neglect of both mental health and of older people in many areas of policy and resource allocation. We highlighted the opportunities to improve mental health in later life and confirmed that deteriorating mental health is not an inevitable part of the aging process. We are encouraged by the interest that has been shown in the first report and are pleased that Age Concern has agreed to monitor progress in the implementation of our recommendations.

This second report reviews the services available to older people who experience mental health problems. We add our evidence to that of many other organisations in demonstrating the inadequacies of these services in range, in quantity and in quality. And we add our voices to those of others in calling for care that meets older people's needs, that receives a fair allocation of resources and that respects the dignity and humanity of the service users.

We have attempted to provide a broad picture, recognising dementia as an important problem but stressing the high prevalence of depression, much of which is undiagnosed and under-treated. We highlight the plight of many people experience multiple disadvantage because they are older, have mental health problems and also have to cope with other difficulties such as sensory loss or homelessness. These people are currently invisible in UK society, with few advocates to put their case for the fair treatment that should be a hallmark of a civilised society.

Many older people with mental health problems can be helped to maintain an active and productive role in society. Although more resources are needed, much can be achieved by changes in attitude and more imaginative approaches to service delivery.

We are grateful to Age Concern for its continuing support of this inquiry and for its commitment to monitor progress in this field and to work with others to press for improvements.

I would like to thank the many individuals who have supported this Inquiry and given unstintingly of their time and energy. I am most grateful to all the members of the Inquiry Board, the Advisory Group and our Government participants. Sir William Utting CB, the Deputy Chairman of the Board, has throughout been a source of immense experience and wisdom. It has been a great privilege to work with such colleagues.

The Board members all join me in thanking our secretariat. Philip Hurst, from Age Concern England has provided valuable up-to-date information about policy on ageing at a time of rapid change. Michele Lee, the project manager, has worked with great energy and determination. Any success that we achieve will be mainly thanks to her hard work.

We hope that our work will generate action as well as interest, and will thus achieve our prime aim of improving the well-being of older people with mental health problems.

Dr June Crown CBE Chairman of the Inquiry

Executive summary

This is the second and final report of the UK Inquiry into Mental Health and Well-Being in Later Life. The Inquiry was launched in late 2003 as a result of concern that mental health in later life is a much neglected area. It published its first report, *Promoting Mental Health and Well-Being in Later Life*, in 2006.

This report sets out to answer an important and timely question: How can we improve services and support for older people with mental health problems?

The Inquiry's vision is of a society where the needs of older people with mental health problems and the needs of their carers are understood, taken seriously, given their fair share of attention and resources, and met in a way that enables them to lead meaningful and productive lives. The Inquiry believes that this can be achieved, and that this achievement will benefit society as a whole.

Why is this important?

Older people's mental health is an increasingly important area of public policy that does not get the attention it deserves. Three million older people in the UK experience symptoms of mental health problems that significantly impact on quality of life, and this number is set to grow by a third over the next 15 years. This represents an enormous cost to society and the economy, in direct costs to public services and indirect costs in lost contributions from older people who boost the UK economy by over £250 billion each year as workers, volunteers, unpaid carers and grandparents. At a time when the Government wants to make the most of older people's contributions to society, the neglect of older people's mental health needs represents a waste of human potential that we cannot afford.

This report draws on evidence from older people, carers, organisations and professionals, and makes recommendations for ways to improve services and support for older people with mental health problems.

Facts, figures and policy

The range of mental health problems experienced in later life is very wide. It includes depression, anxiety, delirium (acute confusion), dementia, schizophrenia and other severe mental health problems, and alcohol and drug misuse. This report presents a comprehensive review of key facts and figures relating to each of these, as well as facts and figures on services and sources of support.

There is tremendous unmet need in every area:

- One in four older people living in the community have symptoms of depression that are severe enough to warrant intervention.
- Only a third of older people with depression ever discuss it with their GP.
 Only half of them are diagnosed and treated, primarily with anti-depressants.

- Depression is the leading risk factor for suicide. Older men and women have some of the highest suicide rates of all ages in the UK.
- Dementia costs the health and social care economy more than cancer, heart disease and stroke combined.
- Fewer than half of older people with dementia ever receive a diagnosis.
- A third of people who provide unpaid care for an older person with dementia have depression.
- Delirium or acute confusion affects up to 50 per cent of older people who have operations.
- There are approximately 70,000 older people with schizophrenia in the UK.
- People aged between 55 and 74 have the highest rates of alcohol-related deaths in the UK.
- It is agreed that rates of both prescription and illicit drug misuse in later life are under-estimated but few if any definitive statistics exist.

The UK four nations face common challenges in developing policies on older people's mental health but have proposed some different solutions. There is commitment to age equality in policy. Strong leadership is needed throughout the system to deliver the intended outcomes in practice.

The Inquiry has identified five main areas for action.

Ending discrimination is the first priority. Older people with mental health problems face discrimination in policy, practice and research. Direct age discrimination, such as age barriers to accessing services, can have a devastating effect:

"Going to a group and mixing with others who had similar problems as me was good. And having someone to talk to — I liked my support worker. But I can't get that now because of my age... I feel alone and isolated. I feel as if there's no reason to get up. I feel terrible... I feel suicidal. I was going to harm myself recently."

Older people also face indirect age discrimination and ageist attitudes:

"Mum drinks a lot. I think it's abuse. It's interesting when I tell people as they say things like, 'If that helps her then let her'. I wonder if it would be the same reaction to someone younger?"

Stigma has a terrible impact. It interacts with ageism to make older people with mental health problems invisible.

"The thing is if you've got a broken arm you've got people wanting to help – 'Let me cook you a meal'. But if you've got a broken heart and a broken head they just don't want to know."

What needs to be done?

- Remove age barriers to accessing services
- Ensure that specialist services for older people are properly resourced
- Tackle the stigma attached to mental health issues
- Pay more attention to invisible groups like older people with alcohol and drug misuse problems, and people growing older with severe mental health problems

Prioritising prevention is essential. Many mental health problems in later life can be prevented. The risk factors for depression, anxiety, suicide, delirium and some types of dementia are well known. Social isolation is a common risk factor across a range of problems. The problems are diverse but all of them require preventative action at multiple levels, from the individual to the broader policy level.

"It helps me to be able to talk to someone... even having someone that I could get hold of on the phone would be good... I feel I should get help to keep things going rather than waiting for things to go wrong before I get support. I feel isolated."

What needs to be done?

- Challenge the widespread defeatism which leads people to believe that mental health problems are an inevitable part of growing older and therefore nothing can be done
- Reduce isolation and strengthen social support for older people
- Focus on preventing depression and delirium

Enabling older people to help themselves and each other is important. Only a small percentage of older people with mental health problems receive help through formal services. The vast majority cope using their own resources, so support for self-help and peer support is necessary.

"Use it or lose it! I work myself to the bone, and it works for me. Seven years on [from being diagnosed] I'm still living with dementia, not dying from it." Older people point to the importance of participation and relationships. Peer support from others who have had similar experiences is particularly valued. Providing support for friends, family and other unpaid carers is crucial given the major role they play in caring for older people with mental health problems. Unpaid carers themselves are often older and also at risk of developing mental health problems.

What needs to be done?

- Put more emphasis on community development initiatives that enable older people to help themselves and each other
- Promote peer support
- Provide support for unpaid carers

Improving current services is necessary. Although only a minority of older people with mental health problems access them, housing, health and social care services can play an important role. Primary care is where many older people turn to for help and providers play a crucial role in the initial identification of mental health problems and the co-ordination of care. Social care helps older people to maintain independence and well-being but services are under pressure. Housing support enables older people with mental health problems to live in their own homes but its role is often overlooked. Acute hospitals and care homes are important settings because so many older people there experience mental health problems. There is considerable scope for improving all of these services. The challenge is to provide services that older people want.

"I went to my doctor and he suggested Prozac. I told him no medication, especially Prozac. He's a nice enough guy usually, but when I said I just wanted to talk to someone, he totally patronised me."

What needs to be done?

- Develop interventions at the individual and systemic levels
- Develop models of collaborative working with mental health specialists
- Pay more attention to the role of housing support

Facilitating change requires action in several areas. We should feel optimistic about change as there are many opportunities, with policy emphasis on age equality and self-directed support. Improved education, training and support for those who work with older people will facilitate change. Stronger professional, managerial and political leadership is essential, as is the effective targeting of much-needed investment.

What needs to be done?

- Provide education, training and support
- Increase investment
- Strengthen leadership

Conclusions

The levels of unmet mental health needs amongst older people are extremely high. The facts about mental health problems in later life should generate a sense of urgency and of anger about the lack of attention paid to them. Yet there is still a resounding silence.

Age discrimination remains the fundamental problem. It comes in various forms, all of which must be tackled.

One in four people aged 65 and over have symptoms of depression, much of which could be prevented. This demands the development of a public health approach to depression in later life.

The majority of older people with mental health problems do not receive services. We need to shift our attention to them, to ensure that they are supported by loved ones and enabled to care for themselves – by design, not by accident or neglect.

We need to take action on the mental health problems for which there is strong evidence of what works (such as depression, anxiety, delirium, dementia) and we need to pay more attention to problems that have been invisible to date but which will become more pressing in the future, such as older people with alcohol and drug misuse problems and people growing older with severe and enduring mental health problems.

There is no time to waste. As our population ages, we must ensure that the numbers of older people who suffer mental health problems are minimised. Mentally healthy ageing will make a key difference between a society that is able to ensure that later life is enjoyable and fulfilling and one that is not.

Recommendations

The Inquiry makes 35 recommendations which are listed in Chapter 9 and on pages 9-12, along with the recommendations from the Inquiry's first report.

Age Concern have agreed to audit responses to these recommendations and report on progress in 2009.

List of recommendations - First report

Who	No.	What
ocitivocht ochoo	Ψ-	Establish "Healthy Ageing" programmes, involving all relevant local authority departments, in partnership with other agencies.
	N	Identify funding for and support community-based projects that involve older people and benefit their mental health and well-being.
	က	Introduce a duty on public bodies to promote age equality by 2009. See Recommendation 4 from the Inquiry's second report.
	4	Ensure that the Commission for Equality and Human Rights tackles age discrimination as an early priority in its work programme. See Recommendation 6 from the Inquiry's second report.
Government	2	Ensure that the 2007 Comprehensive Spending Review takes into account the findings of this Inquiry, and commit to setting a target date for ending pensioner poverty. Government should publish, by 2009, a timetable for achieving this and report on progress against milestones.
	9	Work to achieve consensus, both within Government and with external stakeholders, on long-term pension arrangements.
The state of the s	2	Ensure that active ageing programmes promote mental as well as physical health and well-being in their design, delivery and evaluation.
	∞	Ensure that mental health promotion programmes include and provide for older people. See Recommendation 10 from the Inquiry's second report.
Education departments	0	Ensure that school programmes promote attitudes and behaviour that will lead to good mental health and well-being and healthy ageing.
- C	10	Encourage work practices that support a healthy work-life balance for employees, as a contribution to long-term mental health and well-being.
Fublic bodies	-	Abolish mandatory retirement ages and enable flexible retirement for older employees.
	12	Provide pre-retirement information and support for all employees.
Public bodies and businesses	13	Educate and train all staff who have direct contact with the public to value and respect older people. See Recommendation 32 from the Inquiry's second report.
Age Concern and the Mental Health Foundation	4	Work with other organisations, including the media, to improve public attitudes towards older people and promote a better understanding of mental health issues. See Recommendation 24 from the Inquiry's second report.
Voluntary organisations and local authorities	15	Encourage and support older people to take advantage of opportunities for meaningful activity, social interaction and physical activity; and provide information, advice and support to enable people to claim the benefits to which they are entitled.

List of recommendations - Second report

Recommendations 1, 3, 5, 18 and 31 require immediate attention.

Who	No.	What
	-	Establish, by 2008, a high-level task force, led by a Government minister, to co-ordinate and drive the development and improvement of services and support to meet the mental health needs of older people and promote good mental health in later life.
	2	Ensure that one minister has responsibility for mental health issues for adults of all ages.
Government	က	Ensure that the principle of age equality is incorporated into all mental health policies, performance indicators, strategies and initiatives across Government by 2008, and ensure that older people's specific needs are identified and addressed.
	4	Introduce a duty on public bodies to promote age equality by 2009. See Recommendation 3 from the Inquiry's first report.
	2	Increase investment in services and support for older people with mental health problems and their carers, to ensure equality with younger adults.
Commission for Equality and Human Rights	9	Conduct an inquiry in 2008 into equality and human rights in mental health services, with a focus on age equality. See Recommendation 4 from the Inquiry's first report.
	7	Develop a comprehensive older people's mental health strategy and establish a body to co-ordinate implementation.
	ω	Require Chief Medical Officers to include older people's mental health and draw attention to late life depression as a public health issue in their annual reports.
Hooth deportments	o	Ensure that national and local suicide prevention strategies and initiatives identify older people as a priority group.
	10	Ensure that anti-stigma and public mental health education campaigns include older people and address late life mental health problems. See Recommendation 8 from the Inquiry's first report.
	-	Support research into overlooked areas of older people's mental health, including the views and experiences of older people and their carers, older people with alcohol and drug problems and people growing older with severe and enduring mental health problems.
NHS	12	Develop the Quality and Outcomes Framework (QOF) of the GP contract to create incentives for GP practices to identify and treat depression and anxiety in accordance with clinical guidelines in order to tackle the problem of under-diagnosis and under-treatment of late life depression.

List of recommendations - Second report (continued)

Who	2	What
	ς.	Ensure that strategies to promote well-being and their relevant performance indicators include and provide for older
	2	people with mental health problems.
NHS and local	14	Support the development of community-based initiatives to reduce isolation and enhance social support for older people who have, or who are at risk of developing, mental health problems.
government	15	Ensure that initiatives that aim to maximise choice and control are offered to and developed for older people with mental health problems, and their carers, with appropriate support where needed.
	16	Involve older people with mental health problems and their carers in the planning, delivery and monitoring of services, with appropriate support where needed.
Housing departments and housing authorities	17	Develop and review national, regional and local housing strategies to ensure that older people's mental health needs are assessed and responded to within general and specialist provision.
	18	Develop a comprehensive commissioning framework for mental health services for all adults which ensures that mental health services that specialise in working with older people are adequately resourced.
:	19	Develop standards that require staff in different settings to work with mental health specialists to recognise, monitor and respond to the known risk factors for depression, anxiety, suicide, delirium and alcohol and drug problems in older people, and monitor compliance.
Health, social care and housing commissioners	20	Develop standards that require services to provide regular surveillance that will prevent physical health problems from developing or deteriorating (potentially affecting or being misdiagnosed as mental health problems) and monitor compliance.
	21	Ensure the provision of flexible home care that offers emotional as well as practical support to older people with mental health problems and their carers at an early stage.
	22	Support the development of information, advocacy, self-help and peer support groups for older people with mental health problems and their carers.
	23	Ensure that suitable mental health services are available and accessible to older people with mental health problems.
Voluntary organisations	24	Work with professional bodies, with the media and with older people to publicise positive stories of hope and recovery from mental health problems in later life. See Recommendation 14 from the Inquiry's first report.
	25	Prepare younger adults with mental health problems for transitions in later life.

List of recommendations - Second report (continued)

Who	No.	What
\$ - C	26	Train staff to recognise and respond to older people's mental health needs, and encourage staff to contribute their skills and knowledge to improving the quality of care provided.
Acute trusts	27	Establish systems and procedures to address older people's mental health needs at all stages of a stay in hospital, from admission through to discharge.
Care homes	28	Establish systems and procedures to ensure that members of staff have the appropriate skills and resources to recognise, monitor and respond to depression in older residents.
Inspection and	29	Ensure that the principle of age equality is incorporated and upheld in all of their policies, assessments and improvement activities and prioritise the assessment of mental health services for older people.
regulatory bodies	30	Develop standards to encourage care providers to develop systems and procedures that facilitate the identification and management of mental health problems that are common in care settings.
Professional regulatory authorities	31	Require the curricula for all basic training programmes to include modules on the assessment and care of older people with mental health needs.
Higher education institutions and training bodies	32	Include the assessment and management of older people's mental health needs in all basic training courses, to ensure the attainment of the necessary skills, knowledge and attitudes to address older people's multiple health problems with care and respect. See Recommendation 13 from the Inquiry's first report.
	33	Develop initiatives to improve the quality of their members' practice in identifying and responding to older people's mental health needs.
Professional bodies	34	Work with members and with other professional bodies to define the specialist skills and knowledge involved in working with older people with mental health problems, and educate colleagues who work with younger adults to ensure that older people are not indirectly discriminated against in the services they receive.
	35	Establish programmes to develop and strengthen leadership in working with older people, including older people with mental health problems.

Chapter 1 Introduction

The UK Inquiry into Mental Health and Well-Being in Later Life was established in late 2003 to investigate the neglect of older people's mental health in policy, practice and research. It published its first report, *Promoting Mental Health and Well-Being in Later Life*¹, in 2006, drawing on evidence from older people, carers, organisations and professionals to make recommendations for ways to make positive mental health and well-being a reality for all older people in the UK.

While the majority of older people experience good mental health and well-being, a significant minority do not. This second and final report is concerned with this group. Taking the views and experiences of older people and carers as its starting point, the report makes recommendations to a wide audience for ways to improve services and support for older people with mental health problems.

1.1 Why is this important?

Over a third of older people in the UK experience symptoms of mental health problems such as depression, anxiety, delirium (acute confusion), dementia, schizophrenia, bipolar disorder, and alcohol and drug (including prescription drug) misuse. As the absolute number of older people in the population grows, from 9.6 million in 2005 to 12.7 million in 2021, the number of older people with mental health problems will also grow. Within the next 15 years, over six per cent of the total UK population, or one in every 15 people, will be an older person experiencing a mental health problem.²

The impact will be felt in the direct and indirect costs to individuals and their families, statutory service providers, businesses, voluntary organisations, government and wider society. Mental health problems in later life can be extremely disabling, resulting in poor quality of life, isolation, exclusion, despair and even premature death. An increase in the number of older people with mental health problems will magnify these personal costs to individuals and their families. It will also lead to increased housing, health and social care costs, with further pressure on areas such as transport and leisure. Demand on the workers who provide these services will be increased.

These direct costs will be compounded by indirect costs to the economy in lost contributions from older people totalling more than £250 billion per year. People aged 50 and over contribute £230 billion per year, or around a quarter of the total UK economy.³ Their contributions as unpaid carers, grandparents and volunteers total £24 billion per year.⁴ Older people boost the economy by an additional £245 billion per year in consumer spending.⁵

We risk losing the unquantifiable wealth of experience and wisdom that older people bring to our families and communities which helps to maintain and improve the mental health and well-being of others. For example, children of depressed parents have a 50 per cent risk of developing depression themselves before the age of 20⁶ but grandparents, who provide an average of 16 hours of child care per week,⁷ have been shown to moderate the transmission of depression from mothers to their children.⁸ Grandparents who are depressed themselves are much less likely to be able to have this protective influence.

Every member of society will be affected in some way. Government will find it difficult, if not impossible, to carry out policy commitments and meet key targets. At a time when the Government is recognising society's increasing reliance on older people's contributions and aiming to make the most of them,⁹ the neglect of older people's mental health needs represents a waste of human potential that we simply cannot afford. When the Government is encouraging charities to take a more active role in the design and delivery of public services,¹⁰ we cannot ignore the mental health of older people, who make up 74 per cent of the volunteer workforce in health and social services,¹¹ the main areas where voluntary organisations are involved. If we continue to waste the opportunities presented to us by the growing numbers of older people, we will store up problems for the future and our financial and human resources will come under serious strain.

The good news is that mental health problems are not an inevitable part of ageing. Many older people with mental health problems who receive appropriate support are able to lead productive and fulfilling lives. We need to prevent or delay the onset, recurrence and worsening of mental health problems in later life to ensure older people and carers are able to contribute fully to society.

However, there is no time to waste. The scale of the problem is huge and current provision of services and support is insufficient to meet current and future needs. There is little sign of adequate planning for the future, especially for people growing older with severe and enduring mental health problems. Services are fragmented or non-existent for many. Age discrimination in mental health persists. Progress is hampered by the defeatist assumption that mental health problems are a normal part of growing older and that there is no effective treatment. Workers feel overwhelmed and unsupported. Unpaid carers are particularly stressed. Responsibility for the issue is blurred, with confusion about leadership at every level.

1.2 Call to action

The Inquiry's vision is of a society where the needs of older people with mental health problems, and the needs of their carers, are understood, taken seriously, given their fair share of attention and resources, and met in a way that enables them to lead full and meaningful lives. The Inquiry believes that this can be achieved, and that this achievement will benefit society as a whole.

We need a radical shift to produce decisive action and measurable improvement in the lives of older people and their carers. Action requires creativity, imagination and will. This shift is starting to happen in some places and we know that change is possible.

1.3 Evidence in this report

This report draws on a wide range of evidence including:

- A comprehensive literature and policy review commissioned by the Inquiry;¹²
- Evidence from older people and carers gathered from a fieldwork study commissioned by the Inquiry which included interviews with more than 200 older people in four sites across the UK, questionnaire responses and additional scoping of published and unpublished research;¹³

- Evidence from organisations and professionals gathered from roundtable discussions, a call for practice examples, questionnaire responses and additional research:
- The knowledge, experience, advice and guidance of more than 80 Board members, Government participants and Advisory Group members (listed in the Acknowledgements);
- The knowledge and experience of members of the Age Concern Mental Health and Well-Being Network; and
- Consultation with various audiences through meetings, presentations and workshops.

Based on this evidence, the Inquiry has identified five main areas for action:

- Ending discrimination
- Prioritising prevention
- Enabling older people to help themselves and each other
- Improving current services
- Facilitating change

Following Chapter 2, which outlines key facts, figures and policy developments, these five areas form the structure of the rest of the report (Chapters 3-7). Chapters 8 and 9 present the Inquiry's conclusions and recommendations.

Chapter 2 Facts, figures and policy

Key points

- The number of older people with mental health problems in the UK will increase by a third over the next 15 years to 4.3 million, or one in every 15 people.
- Mental health problems in later life are very diverse and there is tremendous unmet need.

This chapter sets out key facts, figures and policy on older people's mental health in the UK, which provide the context for the rest of this report. 'Older' is defined as aged 65 and over unless indicated otherwise. This definition is consistent with the way services are currently organised although, as we shall see in Chapter 3, this chronological age marker can also create problems.

2.1 Prevalence

A wide range of mental health problems may affect people in later life. They include depression, anxiety, delirium (acute confusion), dementia, schizophrenia, bipolar disorder, and alcohol and drug misuse. Suicide, self-harm and self-neglect are common among older people and are often the result of mental health problems. Many people develop mental health problems for the first time in later life, while others grow older with them.

Table 1 shows the prevalence rates of different mental health problems for older people in three settings: the community (usually private households but also including sheltered and extra-care housing), acute hospitals, and residential and nursing care homes.

For people living in the community, a distinction is made between those who meet the clinical criteria for a formal diagnosis of the problem and those who experience symptoms, only some of whom will meet the clinical criteria.

Table 1 also shows the gaps in current data. Many of the prevalence rates are estimates, based on small qualitative studies, or not known at all.

Table 1. Percentage of people aged 65 and over with different mental health problems in the community, acute hospitals and care homes

	Community (Clinical criteria)	Community (Symptoms)	Acute hospitals	Care homes
Depression ^{14,15,16,17}	10-15	25	29	40
Anxiety ^{18,19,20,21}	2-4	10-24	8	6-30
Delirium ^{22,23}	1-2	Unknown	20	'Very common'
Dementia ^{24,25,26}	5	Unknown	31	50-80
Schizophrenia ^{27,28,29}	0.5	2-5	0.4	Unknown
Alcohol misuse ^{30,31}	2-15	Unknown	3	Unknown
Drug misuse				
- Prescription ³²	11	Unknown	Unknown	Unknown
- Illicit ³³	0.1	Unknown	Unknown	Unknown

The number of people aged 65 and over in the UK will increase by a third over the next 15 years, from 9.6 million in 2006³⁴ to 12.7 million in 2021.³⁵ If prevalence rates stay about the same, there will be:

- Approximately 3.5 million older people with symptoms of depression which are severe enough to warrant intervention.³⁶
- About 1.6 million older people who meet the clinical criteria for a formal diagnosis of depression.³⁷
- Nearly 1 million older people with dementia.³⁸
- An estimated 91,000 older people with schizophrenia.³⁹

The actual numbers of older people with symptoms and diagnoses of depression may be greater than projected. The calculations did not take into account that four per cent of older people live in care homes, where depression is much more common. It was also assumed that the prevalence of depression will stay stable over the next 15 years, when in fact there is some evidence that prevalence is increasing.

Significantly, population growth in the next 15 years will be fastest among the groups of older people who are most likely to suffer from mental health problems. These include people aged 85 and over, who are nearly twice as likely to have symptoms of depression⁴⁰ and four times more likely to have dementia than people aged 65 and over;⁴¹ older people from ethnic minority groups⁴² and older prisoners.⁴³ The over-85 population will increase by 50 per cent over the next 15 years, from 1.2 million in 2005 to 1.8 million in 2021,⁴⁴ compared with the 30 per cent increase in the over-65 population. In just half that time, the older black and minority ethnic (BME) population will increase by up to 170 per cent.⁴⁵ The number of prisoners aged 60 and over has increased by 300 per cent in the last 10 years and is expected to continue to increase in the future.⁴⁶

2.2 Depression

Depression is the most common mental health problem in later life. It is best described as a continuum of symptoms, ranging from a major, life-threatening illness to a milder, more chronic condition.⁴⁷ Symptoms include low mood, loss of interest or pleasure in things the person usually enjoys, lack of energy, sleep and appetite disturbances, poor self-esteem and irritability, difficulty concentrating, intense feelings of sadness, guilt, despair, worthlessness and hopelessness, and recurrent thoughts of death or suicide.

Up to 25 per cent of people aged 65 and over living in the community have symptoms which are severe enough to warrant intervention.⁴⁸

- Symptoms of depression are more common in women than men.
- Symptoms of depression increase with age. They affect 20 per cent of people aged 65 to 69, rising to 40 per cent of people aged 85 and over.⁴⁹

Of the 25 per cent of older people who have symptoms of depression, only half (10 to 15 per cent of all older people) meet the clinical criteria for a diagnosis of depression.

- A diagnosis of major (severe) depression requires that a person has had five of a possible nine specified symptoms for at least two weeks.
- A diagnosis of minor (mild) depression is made when a person has had two of six possible symptoms, and depressed mood, almost every day for at least two years.
- Two per cent of older people living in the community meet the criteria for major depression and 11 per cent have minor depression.⁵⁰
- Minor depression becomes more common and major depression becomes less common with age. Depression in later life is thus more chronic, with longer episodes and shorter remission periods, compared with depression in earlier life.⁵¹

The other 10 to 15 per cent of older people who have symptoms but do not meet the clinical criteria for a diagnosis are described as having 'sub-threshold' depression. Policy documents usually cite 10 to 15 per cent as the prevalence rate for late life depression, but there are compelling reasons to pay more attention to all 25 per cent of older people who have depressive symptoms:

- Sub-threshold depression increases the risk of developing major depression.⁵²
- Sub-threshold depression causes just as much suffering and may even lead to greater physical decline than clinical depression.⁵³ It has similar impact on increased use of services, economic costs and risk of death.
- Sub-threshold depression is just as treatable as clinical depression.⁵⁴ We should be concerned with helping all those who might benefit from intervention, rather than just those who meet clinical criteria which may in fact be too narrow to reflect the breadth of human experience.⁵⁵ Focusing on people's experiences of symptoms is a more person-centred and less service-centred approach to treatment.

Depression has a major impact on older individuals and their families:

- It increases the risk of physical health problems like heart disease, diabetes and stroke.⁵⁶ It also slows recovery from illness, increases the risk of readmission to hospital after discharge⁵⁷ and increases the risk of premature death.⁵⁸
- It increases the risk of being a victim of elder abuse. Older people with depression are more than three times more likely to be victims of elder abuse than those without depression.⁵⁹
- It is the leading cause of suicide in older people. Older people with symptoms of depression are 23 times more likely to take their own lives than those without symptoms.⁶⁰

Depression is more common in care settings. At least 30 per cent of older people in acute hospitals and 40 per cent of older people in care homes meet the clinical criteria for a diagnosis of depression. Many more exhibit symptoms.

Depression in older people is under-diagnosed and under-treated.⁶¹

- Two-thirds of older people with depression have never discussed it with their GP.
- Of the third that have raised it, only half (or about 15 per cent of all older people with depression) were diagnosed and are receiving treatment.
- Only six per cent of older people with depression receive specialist mental health care.

The economic costs of depression in later life are not known.

2.3 Anxiety

Anxiety is closely linked to depression in later life and is an under-researched area in its own right. The different types include generalised anxiety disorder, panic, phobias and obsessive-compulsive disorder. Symptoms include worry, apprehension, panic attacks, irritability, restlessness, difficulty concentrating, muscle tension and sleep disturbance.

- Between 2 and 4 per cent of older people living in the community meet the clinical criteria for a formal diagnosis of anxiety.⁶²
- Between 10 and 24 per cent of people aged 65 and over living in the community have symptoms.⁶³
- Sub-threshold anxiety causes just as much suffering as clinical anxiety and should therefore be of equal concern.

Anxiety is more common in women than in men. Most older people suffering from anxiety developed it when they were younger and have grown older with it.

Few studies have examined the impact of late life anxiety on individuals and their families, the extent of unmet need and the economic costs.

2.4 Suicide and self-harm

Globally, suicide rates increase with age.⁶⁴ In most countries, older men have the highest suicide rates of all age groups.⁶⁵ In the UK:⁶⁶

- Men aged 75 and over had the highest suicide rates of all men until 1997. Now men aged 15-44 have the highest rates (19.0 per 100,000 population). Men aged 75 and over have the second highest rates (18.4 per 100,000 population).
- Rates of suicide in older men are highest in Scotland (19.8 per 100,000 population) and lowest in Northern Ireland (8.8 per 100,000 population).
- Women aged 75 and over, and women aged 45-74, have the highest and second highest rates of suicide of all women (7.0 and 6.9 per 100,000 population).
- Rates of suicide in older women are similar across Scotland, England and Wales but lower in Northern Ireland (2.0 per 100,000 population).

These rates mean that 316 men and 198 women aged 65 and over took their own lives in 2004.⁶⁷ These numbers are almost certainly underestimates since the cause of death for older people who die by suicide is often ascribed to known existing physical illnesses on death certificates.

Suicide in later life is marked by distinct characteristics.

- Older people make fewer suicide attempts than younger people but are more successful at taking their own lives.⁶⁸ One in four attempts by older people results in 'completed suicide', compared with one in 15 attempts for the general population.
- Older people, especially men, tend to use more lethal methods such as firearms and hanging. The most common method used by older men is hanging. Older women often die by drug overdose.
- Older people are more likely to be frail and more likely to live alone than younger people. They are less likely to recover from a suicide attempt and less likely to have someone intervene before or during the event.
- Older people who take their own lives are more likely than younger people to have seen their GP in the previous six months, and more likely to present symptoms of physical health problems, while younger people were more likely to present symptoms of mental health problems.⁶⁹

Depression is the leading cause of suicide in older people.

- Between 71 and 95 per cent of older people who die by suicide have a diagnosable mental health problem at time of death.⁷⁰
- Nearly half of older people who take their own lives visit their GP in the month before suicide.⁷¹

Deliberate self-harm (DSH) by older people is more closely associated with suicide than in younger people. DSH by older people should be considered 'failed suicide' unless proved otherwise.⁷²

- Ninety per cent of DSH by older people involves an overdose of medication such as benzodiazepines or other sedatives, paracetemol and antidepressants.⁷³
- Over a third of older people who self-harm have severe depression while 10 per cent are dependent on alcohol.⁷⁴

2.5 Delirium (acute confusion)

Delirium or acute confusion is marked by sudden onset of confusion, disorientation, memory impairment, agitation and even delusions and hallucinations. The causes are almost always physical in nature, including infection and dehydration.

Prevalence increases rapidly with age. Delirium affects between one and two per cent of people aged 65 and over living in the community and up to 14 per cent of people aged 85 and over.⁷⁵

Delirium is very common in care settings. Most research has been done on delirium in acute hospitals.

- Half of delirium cases in older people develop after admission to general hospital.⁷⁶
- Delirium develops in up to 50 per cent of older people who have operations.⁷⁷
- It persists in about a third of hospital patients.⁷⁸
- It is five times more common in older people who have dementia.⁷⁹

Delirium has significant impact on older people's mental and physical health.

- It is associated with increased cognitive decline;⁸⁰ increased risk of medical complications like infections, falls and incontinence;⁸¹ and increased rates of death, both in hospital and after discharge.⁸²
- Older people who experience delirium are less likely to recover from illness and more likely to enter care homes.⁸³
- In one study, 83 per cent of older people who still had delirium when they were discharged from hospital had entered a nursing home or died within a year, compared with 68 per cent of older people who had had delirium and recovered and 42 per cent of older people who had never had delirium.⁸⁴

With proper care, delirium can be prevented in a third of hospital cases⁸⁵ yet it remains under-diagnosed and under-treated.

- It is undiagnosed in over half of older hospital patients.86
- One study found that 84 to 95 per cent of cases of delirium in older people were undetected by attending physicians in general medical units.⁸⁷

The economic costs of delirium are very high:

■ On average, it doubles the length of hospital stay⁸⁸ and costs an additional \$2500 (£1275) per hospital patient.⁸⁹

2.6 Dementia

Dementia is a term for a range of progressive, terminal diseases including Alzheimer's disease, vascular dementia, fronto-temporal dementia (including Pick's disease) and dementia with Lewy bodies. All facts and figures are drawn from the Alzheimer's Society report, *Dementia UK* (2007), 90 unless indicated otherwise.

Prevalence increases rapidly with age. Rates double every five years from age 30 onward.

- Five per cent of people aged 65 and over have dementia, rising to 20 per cent of people aged 80 and over and 33 per cent of people aged 95 and over.
- Two per cent of all people with dementia develop it before the age of 65.
- Two per cent of people with dementia are from black and ethnic minority (BME) groups.

People with Down's syndrome are four times more likely to have dementia and to develop it at earlier ages.

■ Three per cent of people with Down's syndrome in their 30s have dementia, rising to 40 per cent in their 50s and 55 per cent in their 60s.⁹¹

Nearly two thirds (64 per cent) of older people with dementia are cared for in the community, mostly by unpaid carers. More than one third (36 per cent) of older people with dementia live in care homes. Dementia affects 50-80 per cent of people who live in residential, nursing and 'elderly mentally infirm' (EMI) homes.

Dementia has terrible consequences for older people and their friends and families:

- It accounts for more years of disability than almost any other condition, including stroke, cardiovascular disease and cancer.
- It accounts for 10 per cent of deaths in men over 65, and 15 per cent of deaths in women over 65. Delaying onset by five years would halve the number of deaths in the UK due to dementia to 30,000 a year.
- Up to half of people with dementia also have depression. Page 20-25 per cent have major depression and 20-30 per cent have minor or sub-threshold depression. People with both dementia and depression have higher rates of disability and decline and higher rates of hospitalisation than people with dementia alone.
- A third of people who care for an older person with dementia have depression. 95

Yet dementia is often undiagnosed and under-treated.

■ Fewer than half of people with dementia will ever receive a diagnosis. 96

The economic costs of dementia are extremely high⁹⁷:

- In the UK, dementia costs £17 billion per year.
- Accommodation costs equal £7 billion (41 per cent of the total). Friends and family provide unpaid care worth £6 billion (36 per cent) and health and social care costs add up to £4 billion (23 per cent). Dementia costs the health and social care economy more than cancer, heart disease and stroke combined.⁹⁸
- The balance of health and social care spending on dementia differs from other mental health problems. The NHS accounts for 35 per cent and local authorities for 65 per cent of health and social care spending on dementia services. In contrast, the NHS accounts for 80 per cent and local authorities 20 per cent of spending on 'adult' mental health services.⁹⁹
- Dementia services are not judged to be delivering value for money.

2.7 Schizophrenia and other severe mental health problems

Schizophrenia, bipolar disorder and other severe mental health problems in later life are an under-researched area. Relatively few older people suffer from these conditions but those who are affected in later life have very complex needs. People who have grown older with schizophrenia may be 'graduates' of asylums or long-stay mental hospitals, and now living in specialist care homes. They may suffer from side effects of long-term use of anti-psychotic drugs.

The prevalence of schizophrenia and bipolar disorder does not appear to increase with age. About one per cent of people aged 65 and over in the community have psychotic disorders. About 0.5 per cent have schizophrenia.¹⁰¹

- Three-quarters of older people with schizophrenia developed it in their teens or 20s ('early onset') and have grown older with it, 15 per cent developed it between age 40-64 ('late onset') and 10 per cent developed it for the first time after 65 ('very late onset').¹⁰²
- The majority of older people with schizophrenia are women. Men with early onset schizophrenia have very poor outcomes and are less likely to survive into later life. Women predominate among those with late or very late onset schizophrenia.

Schizophrenia and bipolar disorder often occur with other mental health problems. Co-morbidity is associated with poorer outcomes.

- Sixty per cent of older people with schizophrenia have major depression during the course of their illness.¹⁰³
- A significant percentage, especially of men, also have alcohol and drug problems.
- Thirty per cent of older people with bipolar disorder have other mental health problems: nine per cent have substance misuse problems, five per cent have post traumatic stress disorder, 10 per cent have anxiety and five per cent have dementia, in addition to bipolar disorder.¹⁰⁴

■ People with severe mental health problems are more likely to have physical health problems such as cardiovascular disease and diabetes.

The majority of older people with schizophrenia live in their own homes.

■ In one study, 55 per cent of older people with schizophrenia lived in the community, 30 per cent in care homes and 15 per cent in long stay psychiatric wards or community hospitals.¹⁰⁵

The economic costs of schizophrenia in later life are not known. Research on younger people shows that public expenditure on each person who is newly diagnosed with schizophrenia is £23,000 per patient per year for the first five years. ¹⁰⁶ If this figure is applied to the total number of older people with schizophrenia in the UK, it suggests a cost of around £1.5 billion per year.

2.8 Alcohol and drug misuse

There are no definitive prevalence statistics on alcohol and drug misuse in later life due to variations in the populations sampled and the methods of detection used. There are also inconsistencies in the terms used, including consumption, use, misuse, overuse, abuse, dependence and addiction. The distinction between intentional and unintentional misuse is also often unclear.

Alcohol misuse is estimated to affect between two and 15 per cent of older people living in the community.¹⁰⁷ In clinical settings, estimates range from four to 23 per cent.¹⁰⁸

- Symptoms of alcohol misuse include accidents, malnutrition, self-neglect, depression, insomnia, and confusion. These can be hard to distinguish from symptoms of other health problems.
- Ten to 30 per cent of older people who misuse alcohol become depressed.¹⁰⁹ In one study, nearly three-quarters (71 per cent) of older people discharged from a psychiatric hospital who had been diagnosed with alcohol or drug problems also had depression.¹¹⁰
- Older men are more likely to misuse alcohol than women. Older Irish men are at particularly high risk of both alcohol problems and depression.¹¹¹

On average, older people consume less alcohol than younger people but have higher rates of alcohol-related deaths.

- People aged 65 and over consume fewer units of alcohol per week than younger people, but they drink more frequently. Older people are more likely than younger people to drink every day.¹¹²
- While moderate intake may have a beneficial effect on health, older people are more susceptible to the effects of alcohol than younger people, due to a slower metabolism and the potential for adverse interactions with prescribed medications.

Alcohol misuse in later life can have grave consequences:

- It is one of the leading causes of falls in older people. 113
- It is closely associated with depression and suicide in older people. 114
- People aged 55 to 74 have the highest rates of alcohol-related deaths in the UK.¹¹⁵

Suffering may be needless. Older people respond just as well to treatments for alcohol problems as younger people but they rarely receive them. In one study, only 10 per cent of older people with a diagnosis of alcohol misuse disorder were referred by psychiatrists to specialist alcohol services.

Drug misuse in later life encompasses a range of scenarios including:

- Use of mis-prescribed medication
- Accidental misuse of over-the-counter and prescribed medications such as benzodiazepines or other tranquilisers
- Intentional misuse of over-the-counter and prescribed medications
- Intentional misuse of illicit drugs such as cannabis and cocaine.

All of the available evidence asserts that rates of both prescription and illicit drug misuse are under-estimated but there are few definitive statistics.

Misuse of prescription drugs is a particular risk for older people because they take many more medications than younger people.

- Nearly 80 per cent of people aged 65 and over in the community are taking prescribed medicine and a third take four or more prescribed medicines at the same time. In care homes 96 per cent of older people take prescribed medicine and 71 per cent take four or more at the same time. ¹¹⁸
- At least 10 per cent of older people have not had their medicines frequently assessed and are taking inappropriate medication as a result.¹¹⁹
- At least 25 per cent of older people are taking psychoactive drugs, such as antidepressants or sedatives. 120
- Sedatives like benzodiazepines are often over-prescribed for and misused by older women.¹²¹ Neuroleptics (anti-psychotics) are often over-prescribed in hospitals and care homes.¹²²

Illicit drug misuse is not common in older people and most often seen as a problem in younger people. However, the numbers are expected to increase as the 'baby boom' generation grows older.¹²³

- Cannabis is the most commonly used illicit drug in later life.
- Older men are more likely to have illicit drug problems than women.

2.9 Services and support

This section focuses on a wide range of services and support for older people with mental health problems and their carers. There is limited data on service provision and use for this group. Data is often categorised either for older people or for people with mental health problems.

2.9.1 Unpaid care

The majority of older people with mental health problems rely on unpaid care from friends, family and neighbours, or do not receive any support at all.

Unpaid carers of older people with mental health problems are often older themselves:

- One in five of all male carers and one in six of all female carers are aged 65 and over.¹²⁴
- Older carers provide more hours, and more intensive care, than younger carers. A third of carers aged 65-74, and half of those aged 85 and over, provide more than 50 hours of care a week.¹²⁵
- Two-thirds of carers who provide more than 50 hours a week say that caring has affected their health. 126
- Carers aged 65 to 74 are more likely to be women. Carers aged 75 and over are most likely to be men. 127

Older carers save the economy £15 billion per year. 128

Many carers are also at risk of developing mental health problems themselves.

- Unpaid carers have poorer health than people who are not carers; stress, fatigue, loneliness and financial worries are particularly common in older carers. 129
- Caring for a person with dementia is particularly stressful. A third of people who care for an older person with dementia have depression.¹³⁰
- Older unpaid carers are more likely to be from deprived areas.¹³¹

2.9.2 Housing

Housing plays an important though under-recognised role in supporting older people with mental health problems.

- Poor quality housing is associated with depression in older people. 132
- The majority of older people with mental health problems live in their own homes in the community. Almost two-thirds (64 per cent) of older people with dementia live in the community and one-third (36 per cent) live in care homes.

Specialist housing provision for older people with mental health problems is an underresearched area. There remains tremendous unmet need.

2.9.3 Primary care

Primary care is the main community-based service used by older people with mental health problems.¹³³

- Older people visit their GPs more often than younger people. They visit seven times a year on average, ¹³⁴ compared with four times a year for all age groups. ¹³⁵
- Approximately 2.1 million older people, or 22 per cent of all people aged 65 and over, visited their GP in the last two weeks. ¹³⁶
- Around 40 per cent of older people who visit their GP have mental health problems.¹³⁷

Many late life mental health problems are missed in primary care:

- Only a third of older people with depression discuss it with their GP and less than half of them are treated for depression.¹³⁸
- Nearly half of older people who take their own lives visit their GP in the month before suicide.¹³⁹
- Less than 50 per cent of older people with dementia are diagnosed. 140

Even when older people are offered support, it is frequently drug therapy, without adequate consideration of other suitable interventions.¹⁴¹

2.9.4 Social care

Social care is extremely important for ensuring that older people with mental health problems are able to maintain quality of life.

It is difficult to determine what percentage of social services is used by older people with mental health problems. Data sources are usually divided between two categories: older people and people with mental health problems.

However, it is known that the majority of social services are provided to older people, and a significant percentage of them have mental health problems. The costs are high.

- Nearly three-quarters (72 per cent) of people who use social services are aged 65 and over.¹⁴²
- Nearly 60 per cent of social care spending is on older people.¹⁴³
- The cost of services for older people with mental health problems is consistently higher than for physically frail older people. 144

There remains tremendous unmet need:

- Only 15 per cent of older people are in regular contact with care services at any one time.¹⁴⁵ Only half of those who need care actually receive it.¹⁴⁶
- Social care is increasingly provided only in times of crisis for high levels of need.
 70 per cent of local authorities do not provide help for people with 'moderate' difficulties such as mobility problems.
- A third of people receiving home care experience depression but very few receive any treatment.¹⁴⁸

2.9.5 Specialist mental health care

Specialist mental health services have an important role to play.

 Between 32 and 50 per cent of inpatients in mental health hospitals and facilities are aged 65 and over.^{149, 150}

However, very few older people have access to specialist mental health care:

- Only 6 per cent of older people with depression receive specialist mental health care.¹⁵¹
- Most older people who take their own lives have diagnosable mental health problems but only a small minority are in contact with specialist mental health services.¹⁵²
- There are fewer community mental health teams, crisis resolution teams and assertive outreach teams for older people than for younger people.

2.9.6 Acute hospitals

Older people use many hospital services and many of them experience mental health problems in this setting.

- One in seven older people are admitted to hospital each year. 153
- Older people occupy two-thirds of NHS beds.
- Up to 60 per cent of older people admitted to hospital will have or develop mental health problems. The three most common are delirium, depression and dementia.¹⁵⁴

Acute hospitals are an important setting for interventions. Admission to hospital can provide the first opportunity to diagnose a mental health problem.

However, many older people's mental health needs are not recognised or met.

- Over 50 per cent of older people with delirium are not diagnosed.
- Rates of treatment for depression are as low as 9 per cent. 169

2.9.7 Care homes

Mental health problems are extremely common among older people living in care homes.

- At least 40 per cent of older people in care homes have depression. 155
- 50-80 per cent have dementia.¹⁵⁶
- Up to 30 per cent of residents have anxiety, which is often overlooked.¹⁵⁷
- Care homes are also important settings for people with schizophrenia and other long-term mental health problems who have been discharged from longstay hospitals.

There remains tremendous unmet need.

- Many people are not diagnosed with depression. It is often thought to be symptoms of other health problems, or of old age.¹⁵⁸
- Only half of older people in care homes who are diagnosed with depression receive any kind of treatment.¹⁵⁹

2.10 Policy context

Older people's mental health policy has developed in different ways across the UK. For the most part, it tends to fall in the gap between ageing and mental health policies. However, it must be acknowledged that areas beyond health and social care need to be considered when developing effective policies. Housing, transport, education and leisure facilities and opportunities play a vital role in protecting and promoting good mental health.

The UK's first ageing strategy, *Opportunity Age*, ¹⁶⁰ was published in 2005, with country-specific strategies previously developed in Wales (*Strategy for Older People*, 2003)¹⁶¹ and subsequently developed in Northern Ireland (*Ageing in an Inclusive Society*, 2005)¹⁶² and Scotland (*All Our Futures*, 2007)¹⁶³. All stress the need to maximise the opportunities that an ageing society presents. They emphasise the importance of healthy and active ageing, building on health and social care policies such as the National Service Framework for Older People in England (2001). However, the focus is mostly on the physical aspects of ageing, with little attention paid to older people's mental health needs. ¹⁶⁴

There is no single UK policy or strategy for mental health. The four nations vary in the emphasis they put on mental health improvement and mental health services. For example Scotland has a stronger focus on mental health improvement than the other nations. Key policy documents relating to adult mental health services include the *National Service Framework for Mental Health* in England (1999), *Raising the Standard – the Revised Adult Mental Health National Service Framework* in Wales (2005), *A Strategic Framework for Adult Mental Health Services* in Northern Ireland (2005), and *Delivering for Mental Health* in Scotland (2006).

The definition of 'adult' varies across the UK. In England, Wales and Northern Ireland it refers to 'working age adults' meaning those aged 18 to 65. This definition excludes people aged 65 and over, who are considered 'older people' rather than adults. This has led to age discrimination becoming entrenched in mental health services, with numerous inspectorate reports noting the persistence of this problem. In Scotland however, 'adult' refers to all adults aged 18 and over. Age discrimination in mental health is explored in more detail in Chapter 3.

The exclusion of mental health in policies for older people and the exclusion of older people in some policies for mental health have created the gap into which older people's mental health often falls. Specific policies on older people's mental health have aimed to close this gap, and promote an age equal approach whereby services are provided on the basis of need rather than chronological age. The key policies for each nation are detailed below.

2.10.1 England

The publication of the National Service Frameworks (NSFs) for Mental Health (1999) and Older People (2001) demonstrated the policy gap between the two service areas and triggered this report. Successive reviews of the NSFs have noted that age discrimination in mental health remains a problem.

Current Government policy on older people's mental health in England is set out in the Department of Health document Securing Better Mental Health for Older Adults (2005)¹⁶⁵ which promotes the principle of age equality, stating that services should be based on need, not on age alone. It acknowledges that:

"Older adults with mental illness had not benefited from some of the developments seen for younger adults, and some of the developments seen in older people's services were not fully meeting the mental health needs of older people." 166

Implementation of this policy is supported by *Everybody's Business* (2005), a service development guide which sets out the main components of specialist older people's mental health services in order to help commissioners and providers develop better services.¹⁶⁷

In 2006 the Audit Commission, the Commission for Social Care Inspection and the Healthcare Commission published *Living Well in Later Life*, the report of their joint review of the NSF for Older People. This noted that 'the organisational division between mental health services for adults of working age and older people has resulted in the development of an unfair system, as the range of services available differs for each of these groups'. ¹⁶⁸ In response, the Department of Health published *A New Ambition for Old Age* (2006) which re-affirmed the commitment to the principle of age equality in mental health.

However, this principle has not been applied more widely both within the Department of Health or in mental health strategies and initiatives led by other government departments. They continue to uphold the division between 'adults of working age' and 'older people'. Policies across the board must ensure that older people with mental health problems are not left out of new service developments. The recent appointment of a Department of Health minister with responsibility for both older people and mental health could resolve the remaining gaps and ensure that the principle of age equality in mental health is implemented across government.

In 2005 the Department of Health established a programme board for older adult mental health services to oversee progress. As of 2007 however, the programme board no longer has dedicated support from within the department and its future looks uncertain. Given the historical neglect of older people's mental health issues, the loss of a co-ordinating body is cause for concern.

The recent announcement of a project to produce a national dementia strategy for England is welcome but attention is needed to the whole range of mental health problems that affect people in later life.

2.10.2 Wales

Current policy on older people's mental health in Wales is set out in the National Service Framework for Older People (2007)¹⁶⁹. As in England, separate National Service Frameworks for Mental Health (2002) and Older People (2007) were produced in Wales. However, an effort is being made to close the gap between them. The NSF for Mental Health (and its revised version published in 2005¹⁷⁰) included a standard on providing comprehensive and equitable services 'for all the people of Wales based on need, irrespective of... their age'. The NSF for Older People explicitly states that 'the Welsh Assembly Government is now taking a more integrated policy approach to adult and older people's mental health services, and this standard therefore aims to complement and dovetail with adult mental health policy'. A single minister has responsibility for both older people and mental health, and mental health leads have started to make explicit reference to older people in their work, indicating an alignment of mental health policies and services for people of all ages. The forthcoming Mental Health Promotion Action Plan is expected to include older people and younger adults.

Reviews of progress against the NSF for Older People in Wales must pay particular attention to ensure that age discrimination in mental health is being rooted out. One area of concern is the lack of specific funding for implementation of the NSF for Older People. The NSF emphasises improved use of existing resources within health and social care.

Funding has been provided to support complementary objectives, including £13 million to implement *Well-being in Wales* (2003), a 10-year strategy which includes healthy ageing as one of five key aims. The 2003 Strategy for Older People also received funding for implementation but it did not include an explicit focus on mental health issues.

Meanwhile, £5 million recurrent funding has been provided every year since 2006 to support the delivery of *Raising the Standard*, the revised National Service Framework for Mental Health, which focused on services for 'working age adults'.

Action is needed to ensure that older people's mental health services are not left behind.

2.10.3 Northern Ireland

Policy on older people's mental health in Northern Ireland is under development following the publication of *Living Fuller Lives* (2007), a report on dementia and mental health issues in older age from the Bamford Review of Mental Health and Learning Disability.

Living Fuller Lives is the first national-level report to focus specifically on older people's mental health issues since the Dementia Policy Scrutiny Report in 1994. It sits alongside nine other reports from the Review, including A Strategic Framework for Adult Mental Health Services (2005). A Strategic Framework upheld the distinction between 'adults' and 'older people' and noted that health and social services for people aged 65 and over have developed separately from those for younger adults.

Living Fuller Lives focused on the question of where older people's mental health should sit and concluded that it could be located within either mental health or older people

programmes. Crucially it should be developed as a discrete sub-specialty, with a ring-fenced budget and clear protocols for accessing other programmes of care.

The Review recommends the establishment of a Policy and Practice Development Centre for Mental Health Services for Older People. Further announcements on implementation plans are expected pending the reorganisation of public bodies resulting from the Review of Public Administration (2006).

2.10.4 Scotland

Current policy on older people's mental health in Scotland is set out in *Delivering for Mental Health* (2006), which updates the *Framework for Mental Health in Scotland* (1997). The Delivery Plan identifies the need to take a population based approach to diet, exercise, alcohol use and other issues that are often linked to depression and anxiety. It also prioritises peer support and suicide prevention. It states that older people will be properly taken account of in the work on depression and in respect of their physical health needs. Work to develop dementia services will also be put in place.

The policy in Scotland is to make mental health provision for adults of all ages, including older people. For example, *Delivering for Mental Health* includes a commitment to increase the availability of evidence-based psychological therapies for all age groups. This age inclusive approach to mental health policy makes Scotland unique within the UK. However, the following concerns have been voiced:

- Where mental health policies specifically target older people, they tend to focus on dementia to the exclusion of other mental health problems in later life.
- Older people may not be well served by an age inclusive approach, given the widespread ageist attitudes that exist in society and the fact that services remain loosely structured around the distinction between 'adults of working age' and 'older people'.
- There is a lack of detailed and reliable data on the extent to which older people in Scotland experience mental health problems.¹⁷¹

Scotland has placed greater emphasis on mental health improvement or 'public mental health' than the other UK nations. The country's National Programme for Improving Mental Health and Well-Being funds innovative work including the award-winning anti-stigma campaign **see me**; the public education and training programme Mental Health First Aid; the suicide prevention programme Choose Life; the Scottish Recovery Network; and Breathing Space, a helpline that specifically targets men.

In the spirit of age inclusivity, older people are meant to be integrated throughout, with support from a dedicated programme on later life. However, this has proved difficult to achieve in practice and action is needed to strengthen the links.



Chapter 3 Ending discrimination

Key points

- Older people with mental health problems, especially those with alcohol and drug problems and those growing older with severe mental health problems, are invisible in policy, practice and research.
- Direct age discrimination, indirect age discrimination and ageism must all be tackled to ensure age equality in mental health services.

Older people with mental health problems experience many forms of discrimination. As a result, their views and experiences remain largely invisible in policy, practice and research. This limits both the range and quality of services and support that are available to them, and leads to inequalities both within the older population and between different age groups.

This chapter examines ways to tackle discrimination and ensure that all later life mental health problems are seen, heard and responded to by policy makers, service providers, researchers, older people and their families.

3.1 Current perspectives on discrimination

Discrimination, equality and human rights are rising up the political agenda. The Commission for Equality and Human Rights (CEHR) will start work in October 2007. It will have responsibility in England, Scotland and Wales for tackling discrimination and ensuring equal treatment across six areas of equality: race, gender, physical and mental disability, age, sexual orientation, and religion and belief.

The CEHR will also be responsible for promoting awareness of good practice, holding inquiries and making recommendations to Government on equality and human rights legislation, including recommendations for change.

In Scotland a separate Human Rights Commission is being established and the CEHR will work only on equality. In Northern Ireland these functions are already fulfilled by an Equality Commission and a Human Rights Commission.

There is concern that age equality will be marginalised in the CEHR's work. Progress on tackling discrimination in the six equality areas has been uneven, partly because of the incremental development of discrimination law over the past thirty years. Tackling age discrimination through legislation has been slow compared with steps taken in relation to race, gender and disability, and more recently in relation to sexual orientation, and religion and belief.

Currently, age discrimination legislation applies only to employment and training. A duty on public bodies to promote age equality exists in Northern Ireland, as part of an integrated public sector duty, but not elsewhere in the UK. Yet there are duties on public bodies to promote equality for race, gender and disability.

The Discrimination Law Review (DLR) is examining the case for a Single Equality Act which would consolidate and simplify existing discrimination law and possibly extend protection to areas where none currently exists, such as age discrimination in goods, facilities and services. The effectiveness of a public sector duty covering age would be considerably strengthened if the Single Equality Act included new legislation to tackle age discrimination across all areas of goods and services, including mental health services.

The DLR has raised the possibility of creating an integrated public sector duty to promote equality across all six equality areas, including age. This option would provide a framework for tackling inequality and promoting equality of opportunity for older people with mental health problems.

We need a better understanding of the multiple and overlapping forms of discrimination, including age discrimination and discrimination against people with mental health problems. Many hope that the Single Equality Act will improve the legal tools for tackling multiple discrimination. The CEHR will also have a role in promoting a better understanding of multiple discrimination.

3.2 Age discrimination

Age discrimination is the most common type of prejudice experienced by people aged 55 and over in the UK.¹⁷² The Inquiry's first report found that age discrimination affects all aspects of older people's lives and has a negative impact on their mental health and well-being.¹⁷³

Age discrimination against older people may be defined as any 'action which adversely affects the older person because of their chronological age alone'.¹⁷⁴

■ **Direct age discrimination** is unequal treatment on grounds of age that cannot be justified. An example is an upper age limit on services that disadvantages people over 65.

Indirect age discrimination is apparently neutral practice that disadvantages older people. An example is when it is assumed that older adults can be treated identically to younger adults, and mental health services are organised and designed around the needs of younger people without taking older people's needs and preferences into account.

Ageism refers to negative stereotypes and prejudice towards older people which are based on assumptions about them as a group. An example is the assumption that mental health problems are an inevitable part of ageing. Ageism affects how services are delivered. It is often subconscious and may be benevolent.

Age equality means securing the equal participation in society of people of every age, based on respect for the dignity and value of each individual. It means aspiring to achieve equality in citizenship, access to opportunities and outcomes, as well as respect for their different needs and aspirations. In mental health, it is defined as responding to people on the basis of need, not age, and ensuring that wherever older people with mental health problems are in the system they are not discriminated against and that they have their mental health needs met.

3.2.1 Direct age discrimination

In general, a regulatory approach has been taken to 'root out' age discrimination in the provision of health and social care services. This has proved effective in ensuring that older people have fairer access to some health services such as cardiac procedures and hip and knee replacements.

However, direct age discrimination continues to be entrenched in mental health services, where age-based rules are organised separately for 'general' or 'working age' adults (meaning aged 18 to 65) and older people (aged 65 and over). In 2003 a Northern Ireland Human Rights Commission review of mental health and human rights identified age as one area of inequality. 176

In 2006, *Living Well in Later Life*, a joint inspectorate review of older people's services in England, found that:

"[This] has resulted in the development of an unfair system, as the range of services available differs for each of these groups. For example out-of-hours services for psychiatric advice and crisis management for older people are not as developed as those for adults of working age."

Other services found to be of a lower standard for the over-65s include psychological therapies, crisis resolution or home treatment for people experiencing severe mental health problems, assertive outreach teams that provide intensive support in the community, early intervention teams that provide support to (young) people experiencing severe mental health problems for the first time, rehabilitation, homeless mental health services and alcohol services.¹⁷⁷

Living Well in Later Life observed that:

"Older people who have made the transition between [adult and older people's services] when they reached 65 have said that there were noticeable differences in the quality and range of services available." ¹⁷⁸

For some, mental health services are entirely withdrawn when they turn 65, leaving them with inadequate support at a time when their mental health needs have not diminished and may in fact be increasing.

"[What makes things worse is] being kicked out of my drop-in centre because of my age. Mental illness does not go away at 65!"

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A person with bipolar disorder who has just turned 65 may be told that she can no longer use the day service she has been using because she is now 'too old'.

"The thing was I went to this service for several years, on and off, and then to my horror I discovered that at 65, they no longer take people because 'it's not for pensioners'."

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The abrupt loss of support can have devastating effect:

"Going to a group and mixing with others who had similar problems as me was good. And having someone to talk to – I liked my support worker. But I can't get that now because of my age... I feel alone and isolated. I feel as if there's no reason to get up. I feel terrible... I feel suicidal. I was going to harm myself recently." 181

For those transferred into an older adult mental health service, the situation may not be much better. The older adult service may not be appropriate for their needs, or it may result in a reduced service, as described by one old age psychiatrist:

"Adult mental health teams have better access to occupational therapy, occupational therapy assistants, day centres in the community, psychotherapy services... So when patients are transferred over to us they will sometimes get a reduced level of care. For example, a patient with chronic schizophrenia [was] transferred to us from the adult services [where he] was getting an occupational therapy assistant visiting once or twice a week, a community psychiatric nurse visiting weekly and a consultant visiting every two weeks. Once transferred, the consultant and community psychiatric nurse will visit [once a] month, if you are lucky." 182

In some, more progressive NHS organisations, a person's 65th birthday does not now trigger an automatic transfer between services. Instead, the transfer is based on the people's needs, not their age. However, anyone who develops depression after 65 will automatically be referred to the mental health service for 'older people'.

Age barriers in mental health services also disadvantage younger adults with mental health problems considered to fall within the domain of 'older people's' services. For example, younger people with dementia, and their carers, often have difficulty accessing services that are appropriate to their needs, such as respite care.

In response to reviews such as *Living Well in Later Life*, the Government has declared that ending direct age discrimination in mental health is a priority.¹⁸⁴ Policy documents now promote the principle of age equality in mental health with services that 'respond to people on the basis of need not age and ensure that wherever older people with mental health problems are in the system they are not discriminated against'.¹⁸⁵

Despite these words, the Government has continued to introduce mental health initiatives that focus exclusively on 'adults of working age', sending conflicting messages to commissioners and service providers.

Action is needed across the NHS and particularly local government to ensure that the policy of age equality in mental health is implemented fairly and evenly. Being 'kicked out' of social services at the age of 65 is even more common than losing access to mental health care within the NHS.

Age discrimination at the level of policy and funding needs to be addressed since it sets the context for discrimination in services. The offensive and discriminatory division between 'adults of working age' and 'older people' should be eliminated and replaced with 'adults of all ages' for at least four reasons:

- 1. Older people are adults too. Dividing older people from 'adults', as is done with children and young people, only serves to infantilise and marginalise the older group. This is inconsistent with the Government's commitment to promote age equality.
- 2. Chronological age is an unreliable marker of the start of 'old age'. Many people are staying healthier for longer, making 60 'the new 40'. Others are growing old 'earlier' than the rest of the population due to the effects of poverty, exclusion and poor health. These groups include people from black and minority ethnic communities, people with learning disabilities, prisoners and homeless people.
- 3. The dividing line between work and retirement, once very clear, is becoming blurred. Our ageing population means that workers over 50 represent a third of the UK's potential future workforce, and people may want or need to work for longer. The Government is encouraging this by introducing the right to request working beyond 65 and the ability to postpone receipt of the State Pension in exchange for an enhanced payment. There are plans to raise the State Pension Age to 68. With increasing flexibility in working patterns and lives, maintenance of a rigid distinction between 'adults of working age' and 'older people' is nonsense.
- 4. The division between 'adults of working age' and 'older people' has allowed unfair systems to develop. In England, services developed differently for each group largely because the National Service Framework for Mental Health focused on

'adults of working age' and attracted new investment of around £1.5 billion in real terms. There has been no new targeted investment in mental health services for older people.

At a local level, older people have more limited access to psychological therapies than younger people. Funding criteria used by local authorities when commissioning services leads to over-65s being 'kicked out' of day centres. Often the day centre staff are faced with a difficult choice between withdrawing services from users or continuing to provide services without any funding. Devolution to the front lines of this kind of pressure is unfair to both service providers and users.

An example of what an 'adults of all ages' system might look like already exists in Scotland where mental health policies, like the recent *Delivering for Mental Health* plan (2006), are age proofed to ensure that older people are included in the definition of adults. However, anecdotal evidence suggests that services are still open to indirect age discrimination. Reports on mental health services often do not contain age-specific data, making it difficult to monitor whether older people are receiving an equitable service.

The answer does not lie in policies and service structures alone. Ending direct age discrimination is important but not the whole answer. Action is also needed to target indirect age discrimination.

3.2.2 Indirect age discrimination

Indirect age discrimination is apparently neutral practice that disadvantages older people. For example, if it is assumed that older adults can be treated identically to younger adults, without taking older people's needs and preferences into account.

There is a gulf between the aspirations of policy and the reality. There remains considerable confusion about what age equality should look like in practice. The focus on ending (direct) age discrimination has led some organisations to question whether having a separate mental health service for older people is not in itself discriminatory. Some trusts are tackling age discrimination by decimating older people's mental health services.

The Inquiry condemns this approach as equally age discriminatory. Older people's mental health needs will not be served by moving from the directly discriminatory assumption that older people need *only* older people's mental health services, to the indirectly discriminatory assumption that they can be treated identically to younger adults. Organisations and practitioners must not fall into the trap of indirect discrimination by failing to recognise that some older individuals may require specialist care, for example due to the complications of physical frailty or the need for homebased support.

There is concern that mental health services for 'adults of working age' and older people are being amalgamated without proper recognition and understanding of older people's particular needs. Poor understanding and definition of the specialist skills involved in working with older people is creating confusion and impeding progress. The current nomenclature of specialist services – for example 'old age' psychiatry – does not help.

Specialist services for older people must be properly resourced to ensure that they are not indirectly discriminated against. Specialists who work with older people have skills and knowledge that are required in cases where older people have complex needs resulting from multiple health and social problems such as physical illness, restricted mobility, sensory impairment, cognitive impairment, loneliness and poverty. These specialists bring to their practice extensive training and a deep understanding of people's biological, psychological and social needs in later life and an ability to work collaboratively, for example with social services, housing and voluntary organisations. ¹⁹⁰

The Bamford Review of Mental Health and Learning Disability in Northern Ireland considered older people's mental health services and concluded that they could be located within either mental health or older people's services, but, most importantly, established as a discrete sub-specialty.

The Inquiry recommends that specialist mental health services for older people should sit within mental health services for adults of all ages, rather than parallel to them as they stand now. To minimise the risk of indirect age discrimination, the question of "what are the different needs of some groups of older people" must be asked and answered. Specialists themselves have a responsibility to be clear – with colleagues, commissioners and older people themselves – what their specialties entail. The effect will be much more powerful if co-ordinated across professional boundaries.

A parallel may be drawn with geriatric medicine. It is no longer assumed that all older people should be seen by geriatricians just because they have passed a particular birthday. For the most part, older people see specialists in cardiology, diabetes and other areas for their particular health conditions. But geriatric medicine is still valued as a specialty for older people who have complex needs due to frailty or other circumstances.

Similarly, not all older people with mental health problems should be seen by 'old age' mental health specialists just because they are over 65. For the most part, they should see the practitioners who are best placed to help them with their particular mental health conditions. 'Old age' specialists can play a key role in providing care that is appropriate and tailored for individuals with particular needs.

3.2.3 Ageism

Ageism often underpins direct and indirect age discrimination and can be extremely difficult to root out. It can be very subtle and is not always recognised. Professionals and even older people themselves are often unaware of their own ageist attitudes, which range from:

"patronising and thoughtless treatment from staff, to the failure of some mainstream public services such as transport, to take the needs and aspirations of older people seriously." ¹⁹¹

Policy documents acknowledge that despite progress in tackling direct age discrimination, a change in attitudes has lagged behind. Little attention has been paid to ageism in mental health, which is often expressed as defeatism. It is commonly

assumed that having mental health problems is a 'normal' and inevitable part of what it means to be old. The extension of this logic is that since mental health problems in later life are simply due to being old, there is no use in trying to do anything about it.

"I was told by a doctor, 'What can you expect anyone to do? Dementia is not a treatable disease.'"192

Indeed, older people say that there seems to be widespread pessimism about mental health in later life. ¹⁹³ They find their concerns often dismissed and not taken seriously by their families, neighbours and even GPs. One worker in a voluntary organisation said:

"I had a client who was 84 and had made three suicide attempts. When I spoke to her psychiatrist he said, 'Well, she's old, what do you expect?' And he was a mental health professional! If she had been 48 she would have received immediate help!" 194

This kind of 'therapeutic nihilism' means that problems are allowed to develop and become more severe.

"I feel I am treated differently because of my age. It feels like I'm invisible now and I think sometimes I don't get offered services because I'm old." 195

It also means that unpaid carers may not get the support they need, because the serious nature of mental health problems in later life is not recognised:

"Mum drinks a lot. I think it's abuse. It's interesting when I tell people as they say things like, 'If that helps her then let her'.

I wonder if it would be the same reaction to someone younger?" 196

Closely related are ageist attitudes which hold that older people are not only less likely than younger people to benefit from interventions, but that it is somehow less important that they recover anyway. Older people may internalise these defeatist attitudes and not seek help when they need it as a result. Campaigns to change public attitudes and expectations must target older people. Action must focus on wider inequalities too.

At the broader level of policy and funding, mental health services for older people may be more vulnerable to financial cuts compared with services for younger people. 197 Ageism may also be reflected in the recording and monitoring of service-level data.

Ageism at all levels in society must be tackled to ensure that older people, including older people with mental health problems, are not unfairly discriminated against. This will help sustain improvement in older people's experiences of services. Recent initiatives include a Department of Health campaign to promote dignity and respect

in the care of older people in England, a commitment to launch a public education campaign to improve images of older people in Scotland, the forthcoming appointment of a Commissioner for Older People in Wales and support for a Commissioner for Older People in Northern Ireland.

3.3 Stigma

In addition to age discrimination, the stigma attached to mental illness acts as another major barrier to the improvement of services and support for older people with mental health problems.

"Mental illness is still stigmatised whether you are young or old but older people have a double whammy!" 199

This contrasts sharply with the lack of stigma attached to physical health problems

"The thing is if you've got a broken arm you've got people wanting to help – 'Let me cook you a meal'. But if you've got a broken heart and a broken head they just don't want to know."200

Many older people associate the word 'mental' with madness, which they consider to be irreversible and untreatable and leading inevitably to institutionalisation.²⁰¹

"There is something secret about dementia, people don't want to know and I find it embarrassing to tell them, so I don't."202

Stigma can be particularly acute in close-knit rural communities, and some black and minority ethnic (BME) communities, where mental health problems may be seen as a spiritual failing.

The stigma and fear of dementia is especially significant.²⁰³ Studies suggest that many people with dementia experience a kind of 'social death' as they are seen as 'effectively dead'²⁰⁴ or as pitiful victims who need looking after.²⁰⁵ Friends and even family may distance themselves, making people feel excluded and devalued:

"[When] they know you have Alzheimer's, they just kind of ignore you. You can go to a family affair and everybody is kind of gabbing, gabbing. But they leave you alone because they figure you don't know what is going on... They are frightened, they think you have lost your mind... You are just there and that's it."206

Older people with mental health problems say they would like more positive stories of hope and recovery to combat both the ageism and the stigma they experience on a regular basis. Reducing the stigma of mental illness is a policy priority in all four nations, with national anti-stigma programmes such as **see me** in Scotland, Shift in England and the new Moving People initiative funded by the Big Lottery Fund and Comic Relief, also in England. Public education programmes such as Mental Health First Aid, which teach general members of the public to recognise the symptoms of mental health problems and provide initial help, also help to reduce stigma.

To date, none of these initiatives have focused on older people. This needs to change, because of the impact that stigma has on older people, because older people are the fastest growing age group in the population, and because surveys consistently show that older people hold negative attitudes about mental health.²⁰⁷ Anti-stigma initiatives should build on the work of the Alzheimer's Society and Alzheimer Scotland in promoting a better public understanding of dementia.

"There isn't enough publicity that says what dementia is all about. They don't teach the public right. That is one thing that should be publicised a lot." 208

3.4 Other forms of discrimination

Older people with mental health problems are a diverse group and may experience forms of discrimination in addition to ageism and stigma.

Racial discrimination is very relevant to mental health. Not only does it have a negative effect on the mental health of individuals but there is evidence of racial discrimination in mental health services. Some BME groups have higher than average rates of compulsory admission, lower rates of GP referral, longer lengths of stay in inpatient wards,²⁰⁹ and are more likely to prescribed drugs or electroconvulsive therapy (ECT) rather than psychotherapy or counselling. Racial discrimination fuels a 'circle of fear' that deters many from seeking early treatment for mental health problems.²¹⁰ Older BME people say that being misdiagnosed and 'labeled' with a psychiatric condition can impact on mental health in later life.²¹¹ Race equality in mental health services is a policy priority but more attention is needed to older people's needs.

Gender differences are pronounced. At all ages, women are more likely than men to have mental health problems such as depression and anxiety, and this continues into later life where women outnumber men numerically. Women are more likely to self-harm and misuse prescription drugs. Men are more likely to misuse alcohol and die by suicide. Men are less likely to have strong social networks, making them more vulnerable to isolation and depression in later life, for example after the loss of a spouse or partner. Research suggests that targeted outreach is needed to ensure that older men's mental health needs are not ignored.²¹² However, initiatives to promote gender equality in mental health services have tended to focus on women, and paid little attention to older people at all.²¹³

Older people with mental health problems may experience discrimination due to disability (such as a learning disability or sensory impairment), sexual orientation or religion and belief. Specialist services are often under-developed for these groups.

3.5 Layers of invisibility

Ageism, stigma and other forms of discrimination combine to make older people with mental health problems invisible in policy, practice and research. A review of the existing literature shows that the views and experiences of older people are almost entirely absent.²¹⁴ There remain considerable opportunities for researchers to make contributions in this area.

Godfrey et al. (2005) refer to 'layers of invisibility':

"...some groups, notably those with severe and enduring mental health problems that have persisted into old age [are] metaphorically covered from head to toe; whereas for others, like those with later life depression, their feet periodically emerge from beneath the garments and for yet others, like those with dementia, knee length skirts have replaced the floor length ones." ²¹⁵

None of the issues receives the full attention it deserves. One reason for this may be that older people with mental health problems such as depression or long-term schizophrenia are usually not disruptive or demanding. They do not pose a threat. They are often hidden away from public view and therefore easier to ignore.

"They are not the sort of people that are causing problems in the middle of the night or beating people up but are quietly vegetating and [their] problems are not being addressed."²¹⁶

Older people say that alcohol misuse in later life is often neglected.²¹⁷ Action is also needed to raise awareness of the needs of people growing older with severe and enduring mental health problems, who typify the 'most complex, vulnerable, resource poor and high risk long term service users' in society today.²¹⁸

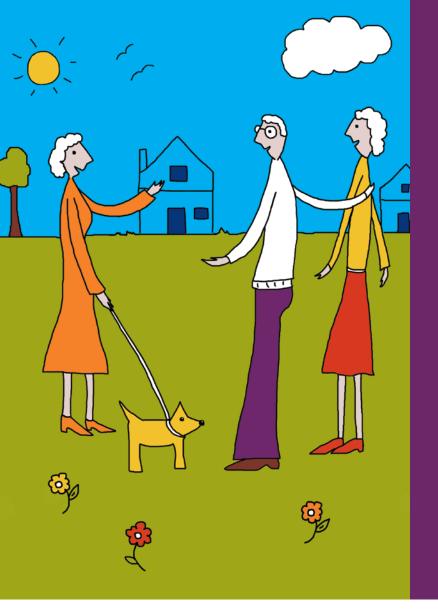
Other invisible groups whose mental health needs are often overlooked include older carers, people growing older with learning disabilities, older veterans, older homeless people and older prisoners. The links between socio-economic factors, exclusion and mental health problems in later life such as dementia and depression need more attention as well. Many will find it surprising to learn that these are not well documented in existing research literature.²¹⁹

Policies on older people's mental health have focused narrowly on dementia and, to a lesser extent, depression. However, the National Service Framework for Older People in Wales (2006) took a broad and inclusive view, explicitly stating that 'older people can have all the mental health problems experienced by adults of working age'.²²⁰ It is hoped that subsequent developments will follow this example. Action is also needed to ensure that artificial boundaries around services are removed and new ones are not created. Such boundaries can exclude older people with mental health needs from both older people's services and mental health services. Awareness and understanding of mental health problems in mainstream services for older people is often lacking, resulting in sub-optimal care.²²¹ For example, older people with mental health problems may be excluded from intermediate care services, even though they may have some of the greatest needs for support after a stay in an acute hospital.

3.6 Making a difference

What can be done for older people with mental health problems to end discrimination?

- Tackle direct age discrimination, indirect age discrimination and ageism in mental health policies and services.
- Ensure proper recognition and resourcing of specialist services that are needed by older people to ensure equal outcomes with people of other ages.
- Outlaw age discrimination in goods, facilities and services and introduce a public sector duty to promote age equality.
- Develop protocols and monitor them to ensure that social care services are not automatically reduced or withdrawn when a person reaches 65.
- Tackle the stigma of mental health problems in later life.
- Run public education campaigns to challenge defeatism.
- Clearly define and possibly rename the 'old age' mental health specialties and locate these within mental health services for adults of all ages.
- Replace the terminology of 'working age adults' with 'adults of all ages'.
- Draw out the views and experiences of older people with mental health problems and their carers.
- Pay more attention to invisible groups such as older people with alcohol and drug problems and people growing older with severe and enduring mental health problems.



Chapter 4 Prioritising prevention

Key points

- There is strong evidence for the prevention of many mental health problems in later life.
- The risk factors for late life depression are very well known.
- Action is needed at individual, community and system levels.

This chapter should be read alongside the Inquiry's first report, which identified factors that help to promote good mental health and well-being in later life. The factors that help to promote mental well-being can also help prevent mental health problems from developing.

Mental health problems are not an inevitable part of growing older, and it is possible to prevent problems, or at least reduce their risk of occurring, in later life. Despite this, very little attention is paid to prevention.

This chapter outlines evidence on action that can be taken to prevent depression and anxiety, suicide, delirium, dementia and alcohol and drug misuse in later life. Prevention of late life schizophrenia and bipolar disorder was outside its scope.

4.1 Current perspectives on prevention

Older people identify freedom from discrimination, active participation, good relationships, physical health and adequate income as important factors that help to maintain mental health and well-being in later life and prevent mental health problems from developing. Older people also value support services that enable them to live in their own homes and carry out the business of everyday life – 'that little bit of help' with tasks like cleaning, DIY, gardening and taking care of pets. 223

"It helps me to be able to talk to someone... even having someone that I could get hold of on the phone would be good... I feel I should get help to keep things going rather than waiting for things to go wrong before I get support."²²⁴

Current Government policies promote independence and well-being for older people, with a shift of resources from acute, hospital-based services to preventative, community-based care closer to people's own homes. While previously, prevention was viewed in terms of avoiding admission to acute hospital or long-term care, numerous policy documents now identify prevention with the promotion of well-being.

In practice the shift to prevention is proving difficult. Intense pressure on resources has forced social services to concentrate on those people with the highest levels of need, inhibiting the shift away from acute services. Low-level support services are losing out. Robust quantitative evidence for the cost effectiveness of prevention is lacking. The long-term nature of prevention precludes evidence of immediate benefit and obvious incentives to act are limited.

The Government's Social Exclusion Action Plan (2006) highlights the importance of prevention and points out that 'early intervention to prevent problems can be seen as having two meanings: early in terms of age or early in terms of the onset of a problem – whatever the age of the individual.'227

Early intervention in mental health however is interpreted as intervention at a young age rather than an early stage in the onset of a problem. Ageist attitudes may lead people to believe that it is less important to prevent problems in older people because it is 'too late' for them. Yet prevention is not only possible, but also beneficial to people of all ages.

The tendency to equate older people's mental health with dementia may inhibit the focus on prevention of mental health problems in later life. Dementia is often seen as inevitable in later life and therefore not 'preventable' in the way that people would usually understand the term, despite evidence that the risks for some types of dementias can be reduced.

4.2 Depression and anxiety

Depression and anxiety often occur together in later life. They affect significant numbers of older people across all settings. The risk factors for late life depression are very well established and they point to the actions that are needed.

4.2.1 Risk factors

Later life is a time of considerable change, marked by life events and transitions such as retirement, physical illness, bereavement and death. While some experiences can be positive, they can also result in loss – of income, health, role, status, purpose, confidence, sense of self, family and friends.

Loss is a key risk factor for depression and anxiety. Depression is linked to the experience of loss, and anxiety is associated with the fear of it.

"I am 66 now and I told the doctors, any doctors that I met, that my whole character has changed since I became 65 [and I had to retire]... I started slashing my wrists. When you worked all your life and suddenly everything comes to a standstill, you wake up in the morning and there is nothing there... It makes me very depressed."²²⁸

Physical disability and illness are the most consistent risk factors for depression in later life.²²⁹ Seventy per cent of older people living in the community have a long-standing disability or illness, and half of them feel limited by it.²³⁰ Rates of disability and illness increase with age and are even higher in care settings. The most common health problems in later life are loss of mobility, loss of vision and loss of hearing. Older people with mobility problems may become housebound and socially isolated and are three to four times more likely to be depressed than those without mobility problems.²³¹ Older people with visual impairments are two to five times more likely to have depression than those without.²³² Older people with hearing impairments are also at risk, with people with dual sensory loss at particularly high risk of developing mental health problems.

Evidence shows that the specific disease or disability itself is much less important than the impact it has on day-to-day functioning. It is the inability to lead a 'normal' life that increases the risk of depression in older people.

"It's not getting ill that worries me – it's being able to get out and about, to do the things that matter to me."233

Increasing disability can make previously simple household tasks, such as unscrewing jars, changing light bulbs and cleaning windows, increasingly difficult. These everyday challenges or 'daily hassles' have been shown to increase the risk of depression in older people.²³⁴

Unsurprisingly, falls, acute illnesses, and diagnosis of life-threatening conditions are also linked to depression and anxiety. The sudden onset of a life-threatening illness can be traumatising²³⁵ and some people develop anxiety as they struggle to come to terms with the possibility of falls, heart attacks and strokes happening again.²³⁶ This can be exacerbated by inadequate access to services, a particular problem for older people in rural areas.

Social isolation and loneliness are other risk factors for depression in later life. Isolation may be particularly acute for older people. One in ten people aged 65 living in the community report feeling often or always lonely, increasing to one in four people aged 80 and over.²³⁷

Bereavement may be the cause of isolation and loneliness. The loss of a spouse, partner, family, friends and pets, to illness or death, can result in the loss of companionship and wider social networks.

"Since my husband died it has been worse. I don't have a sense of purpose or meaning. Being on my own [makes things worse]".238

Loss of friends can be devastating for older lesbians, gay men and bisexuals who tend to rely on friends more than family for social support.²³⁹ Black and minority ethnic (BME) older people must be allowed to grieve in culturally appropriate ways. Other effects of bereavement, such as sudden responsibility for unfamiliar household tasks and disruption to daily routines, can be distressing. Those who do not learn new skills to handle these tasks are at increased risk of long-term mental and physical health problems.²⁴⁰ Bereavement is a particularly important issue in care homes, where turnover of staff and residents is high and relationships are frequently disrupted.

Unpaid carers are at heightened risk of developing mental health problems due to stress, pressure and lack of financial and social support. They may cherish their caring roles but also feel loss, frustration and sadness as their relationship with the person they are caring for changes. Many carers of older people with mental health problems are older themselves and their caring responsibilities can have detrimental impact on their own physical and mental health. Carers of people with dementia are at particular risk; one-third of this group has depression.

Moving into a care home can be a relief but may also involve the loss of neighbourhood and community. Leaving a family home is another loss to be dealt with. Depression is more common in people who have recently moved into a care home, especially if they have moved there from their own home.²⁴¹

Wider factors such as age discrimination, lack of opportunities to participate in society, poverty and social exclusion also impact negatively on mental health in later life. These themes were explored in the Inquiry's first report. They provide the backdrop for individual experiences of depression and anxiety.

"Suddenly here I am, a shadow of the person I used to be and sometimes not even feeling that person... and this awful feeling as I say once you are old you are on the scrap heap really, nobody wants you."²⁴²

4.2.2 Preventing depression and anxiety

Reducing the risk factors. Depression and anxiety can be prevented by minimising the occurrence of risk factors such as physical disability and illness, sensory impairment and social isolation. Physical activity²⁴³ and healthy eating²⁴⁴ protect against depression for people of all ages and should therefore be encouraged. Regular vision and hearing tests can identify potential problems at an early stage and prevent people from being

misdiagnosed as having other communication problems such as dementia. Social networks also help to protect against depression.²⁴⁵ Interventions that target specific groups, use more than one approach and give participants some measure of control are effective in reducing social isolation and loneliness for older people.²⁴⁶

Contact the Elderly: Preventing depression by reducing social isolation

Contact the Elderly works with isolated older people who live alone and have little or no support from family, friends or social services. It provides a low-level intervention to reduce social isolation and improve physical and mental health with particular focus on depression. The project provides home visits and a befriending service run by volunteers. The volunteers organise meetings between older frail people.

For more information, visit www.contact-the-elderly.org.uk

Reducing the impact of risk factors. By minimising the impact of loss and helping older people to stay healthy and play an active role in society, it is possible to prevent depression and anxiety in later life. The key is to enable older people to continue doing the things that are important to them, and to ensure that they have opportunities to sustain relationships or develop new ones. Home care support plays an important role and technology may be able to help;²⁴⁷ aids and adaptations can reduce isolation for older people with sensory impairments²⁴⁸ and Internet technology can enable access to 'virtual' communities for older people who have limited mobility or who live in remote areas.

Targeting individuals at times of risk. Depression and anxiety can also be prevented by targeting people at times when they are at greatest risk. Those who have regular contact with older people need to be aware of the effects that life-changing events such as illness and bereavement can have on mental health. Preparing for major changes like retirement can help ease their impact.²⁴⁹ Emotional support and counselling following events such as losing a loved one or being diagnosed with blindness, along with help to develop the skills to cope with the new demands of daily life, can reduce anxiety.²⁵⁰ Acknowledging and responding to the fear of crime or the fear of falling can help to reduce anxiety that might otherwise become crippling.

Salford Psychology Services for Older People: Preventing anxiety by reducing fear of falling

Salford Psychology Services for Older People have produced a self-help booklet for older people who have had falls. The booklet provides a step-by-step guide to reducing anxiety using a cognitive-behavioural approach.

"The booklet is very, very helpful. I lost my confidence by falling... reading this helped me to regain my confidence. It changed the way I think to make me feel better."

The service has also developed brief training sessions for frontline staff to give them skills in: identifying a fear of falling; helping older people manage their anxious thoughts and feelings; and knowing when and how to refer to specialist mental health services.

For more information, contact Dr Jessica Read, Bolton Salford and Trafford Mental Health NHS Trust, Tel: 0161 772 3481, Email: jessica.read@bstmht.nhs.uk

Interventions in society. Action at the community level and in society as a whole is also needed because:

- Mental health and well-being in later life is influenced by factors like age discrimination;
- Depression and anxiety are so prevalent among older people, especially in care settings; and
- The majority of older people have minor depression which is more amenable to community-based interventions than major depression which is usually treated with medication. A public health approach that targets the whole population rather than just individuals is thus appropriate here. Late life depression should be recognised as a public health issue and tackled in wider areas including education, housing and transport as well as health and social services.

4.3 Suicide

Overall suicide rates in the UK have declined since 1991 but they remain high for older men and women, especially those aged 75 and over. The risk factors for suicide in later life are established and there are clear indications of the actions that are needed.

4.3.1 Risk factors

Depression is the leading cause of suicide in older people. Many of the risk factors for depression are therefore also risk factors for suicide: loss, physical illness and disability, transitions such as retirement, bereavement and social isolation.²⁵¹ Other risk factors include sleep problems such as insomnia, and alcohol consumption, particularly for men. Physical illness is not an independent risk factor for suicide; it usually leads to suicide only when older people are also depressed.

Previous suicide attempts are the best predictor of future suicide attempts in older people.²⁵² Deliberate self-harm is closely linked to suicide in older people so it should be considered a 'failed' suicide unless proven otherwise.²⁵³

Self-destructive behaviour is more likely to lead to death in older people than in younger people because of physical frailty, the greater likelihood of living alone (and therefore fewer opportunities for intervention by others) and greater lethality of intent.²⁵⁴ Older people act less impulsively than younger people in deciding to take their own lives and older men often choose more violent methods, such as firearms or hanging.²⁵⁵ Older women often die by overdose of sedatives such as benzodiazepines.

4.3.2 Preventing suicide

Better prevention, detection, treatment and management of depression will have the most effect on preventing suicides in older people. As with depression, action to prevent suicide is needed at multiple levels, ranging from one-to-one interactions with individuals through to a population-wide or public health approach.

High priority should be given to community-based initiatives that reduce isolation in older people and promote social connectedness and wider social participation. There is evidence of effectiveness for telephone helplines that target isolated and disabled older people to provide regular monitoring and short-term emotional support.²⁵⁷ Evaluation of one such service in Italy over a period of 10 years showed that older women particularly benefited and suicide rates were significantly reduced.²⁵⁸

Follow-up services are needed for both older people who have attempted suicide and those who deliberately self-harm yet there is little evidence that they exist.

Reducing access to lethal means for men and prescription drugs for women will also have positive impact. Primary care providers must take care not to over-prescribe benzodiazepines and other sedatives.

At the broader level, older people must be included and identified as a priority group in suicide prevention strategies across the UK. Public education campaigns are needed to raise general awareness about the risk factors for suicide in older adults, including how to identify them and how to respond appropriately. These campaigns should target friends, family and frontline workers in health, social care, housing, transport, benefits, education, leisure and other people who come into regular contact with older people such as post office and utility workers.

As a society we need to elevate the status of older people, so that suicide in later life will be recognised as the serious problem that it is.

"Suicide in older people is reasonably well understood... What still remains lacking in tackling this devastating problem is concerted and sustained action by each and every one of us to value, support and include older people in all aspects of life." ²⁵⁹

4.4 Delirium (acute confusion)

Delirium is very common in care settings and associated with negative outcomes for older people and increased costs for the care system. It is often preventable. The risk factors for delirium are well known and there is strong evidence for how it can be prevented. This section focuses on the prevention of delirium in acute hospitals.

4.4.1 Risk factors

The risk factors for delirium in acute hospitals are primarily medical. They include many of the conditions that might have led to admission in the first place: acute illness, infection and surgery; and underlying factors such as physical frailty, constipation, dehydration, visual impairment, deafness, intoxication, malnutrition, multiple medications, drugs, pain and sleep deprivation. People with dementia are at greater

risk of developing delirium, and misdiagnosis is common since both dementia and delirium result in cognitive impairment.

Environmental factors such as frequent moves within hospital, an absence of clocks or reading glasses and the use of physical restraints can lead to disorientation and confusion, triggering delirium. Medications such as benzodiazepines and morphine are the precipitating factor in up to 40 per cent of cases of delirium in acute hospitals.²⁶⁰

4.4.2 Preventing delirium

The main approaches to preventing delirium in acute hospitals are primarily clinical. Three approaches are outlined here, with a fourth key approach (educating and training staff) covered in Chapter 7.

Reducing the risk factors. Ways of reducing the main risk factors listed above include: maintaining nutrition and hydration; adapting equipment and improving environmental design to minimise the impact of vision and hearing impairment; managing pain; providing non-pharmacological approaches to sleep and anxiety disorders; providing therapeutic activities; and addressing environmental factors such as reducing moves within hospital and providing clocks in each room. Hospitals carry inherent risks for delirium and early discharge to a home rehabilitation service may be desirable as it is associated with a significantly reduced incidence of delirium.²⁶¹

Hospital Elder Life Program (HELP): Using volunteers to prevent delirium

HELP is a US-based programme that brings a skilled interdisciplinary geriatrics team together with trained volunteers to provide personalised interventions that are tailored to older people's changing needs throughout their hospital stay. Volunteers are trained to provide personal support and attention to older hospital patients including daily orientation, feeding assistance, therapeutic activities, a non-pharmacological sleep protocol and vision and hearing adaptations.

For more information, contact Sharon Inouye, Email: HospitalElderLife@yale.edu, or visit http://elderlife.med.yale.edu

Routine screening and assessment of all older people admitted to general hospitals is recommended, to identify people who may be at risk of developing delirium.

System-level interventions. Hospital-wide approaches to preventing delirium are needed. Improved links between hospital and community services may help ensure that preventative action is taken, where possible, before people are admitted. Commissioners and providers have a role to play in planning and delivering services after discharge from hospital to help prevent older people from developing delirium once they are at home, or in a care home if they have moved there.

Again, a key point is that action is needed at multiple levels to prevent delirium in older people. More attention is also needed to the prevention of delirium in care homes and in the community.

4.5 Dementia

While there is no evidence of ways to prevent dementia, it is possible to reduce some of the risks associated with it. Action to reduce these risks will have benefits for overall health.

4.5.1 Risk factors

The most significant risk factor for Alzheimer's disease is increasing age, together with other factors which cannot be changed such as gender, genetics, having Down's syndrome and other medical conditions such as multiple sclerosis and Huntington's disease.

The risk factors for vascular dementia include age, high blood pressure, obesity and stroke. Most of these are amenable to intervention.

4.5.2 Reducing the risk of dementia

A healthy lifestyle can help reduce the risk of developing vascular and other dementias. Tips include taking regular exercise, eating healthily, drinking in moderation and not smoking. Regular checks on blood pressure and cholesterol levels may also help to reduce risk. Maintaining interests and hobbies, an active social life and mental stimulation, through adult education for example, should all be encouraged.

Population-level screening is not practicable but screening may be targeted at people who are at high risk of developing dementia, such as people with Down's syndrome.

At a broader level, strong public health messages and education campaigns are needed.

Mind Your Head: Educating the public about reducing risks for dementia

The Alzheimer's Society is running a campaign to increase awareness and educate the public about ways to reduce the risk of developing dementia in later life. It stresses the importance of simple lifestyle changes and has produced information sheets including top tips for a healthy lifestyle.

For more information, visit www.alzheimers.org.uk/Mind your head/index.htm

4.6 Alcohol and drug misuse

While the risk factors for alcohol and drug misuse in later life are less established than the risk factors for depression, anxiety and delirium, preventative action is still possible.

4.6.1 Risk factors

The most consistent risk factors for alcohol misuse in later life are: a previous history of alcohol dependence, social isolation and loneliness, social networks that encourage drinking, and unhealthy ways of coping with life events such as retirement or bereavement. Alcohol misuse is closely associated with depression so the risk factors for depression may be relevant here as well. Age-related changes in metabolism and interaction with medication can make older people more susceptible to intoxication even with moderate drinking. Alcohol misuse is more common in men than women. Older people are more likely to drink at home or in someone else's home than younger people. Alcohol misuse is more common in men than younger people.

The main risk factors for prescription drug misuse in later life are a previous history of misuse of sedatives such as benzodiazepines, chronic pain, current alcohol misuse, chronic sleep problems and depression.²⁶⁵ Dependence usually happens as a result of prolonged use leading to increasing tolerance. It is more common in women than men.

The risk factors for illicit drug use in later life are not well known but they include loneliness and previous experience of trauma.

4.6.2 Preventing alcohol and drug misuse

The causes of alcohol and drug misuse are often rooted in earlier life. Thus preventative action must target middle-aged or younger people, to prevent continued alcohol and drug misuse in later life.

A cross-cutting theme is the importance of social support. Community-based initiatives to reduce isolation in older people and develop social networks should be prioritised.

However, the difficulties in doing this should not be underestimated. To prevent alcohol misuse in later life, older people should join social networks composed of non-drinking peers. This may disrupt lifelong ties that have developed and been shaped by trips to the pub and other types of social drinking.

Regular assessment and management of medication use can help to prevent unintentional prescription drug misuse.

At the policy level, alcohol and drug prevention strategies must include and provide for older people. They are currently focused exclusively on younger people and 'working age' adults.

4.7 Making a difference

What can be done to prioritise the prevention of mental health problems in later life?

- Build the evidence base and make the economic case for prevention.
- Challenge defeatism to help people recognise that prevention of mental health problems in later life is possible.
- Recognise the diversity of the mental health problems; prevention may be more possible for some mental health problems than others.
- Enhance social support and reduce social isolation; this will require broad community-based interventions, and will help to prevent depression, anxiety, suicide and alcohol and drug misuse.
- Prioritise older people within existing prevention strategies including those for suicide, alcohol and drug misuse.
- Develop wider public health programmes to tackle the risk factors for depression and anxiety including vision and hearing problems, and reduce the impact of disability and illness by offering counselling and helping older people to develop new skills.
- Develop system-wide approaches to preventing delirium in hospitals.
- Promote healthy living from an early age to reduce the risk factors for dementia, and alcohol and drug misuse.
- Commission more research into the prevention of illicit drug misuse in later life.



Chapter 5 Enabling older people to help themselves and each other

Key points

- The majority of older people with mental health problems live in the community and cope using their own resources.
- How services should enable older people to help themselves and each other is a key challenge for commissioning authorities.

The majority of older people with mental health problems cope on their own or with support from friends, family, neighbours and others. Although in some cases this is because they are unable to access suitable services, for others it is the preferred approach.

This chapter looks at what can be done to empower and enable older people who are experiencing mental health problems, who may or may not have been diagnosed, to help themselves and each other.

Several themes in this chapter echo findings from the Inquiry's first report.

5.1 Current perspectives on self-help and peer support

Older people with mental health problems say that taking an active role in their own recovery is important for their self-esteem.²⁶⁶ Doing things to help themselves and others is one way to make life 'normal'²⁶⁷ and they want to be shown how to make the most of their own resources.²⁶⁸

"I cannot just sit here. I cannot just spend my life sitting here. You've got to do something or find something." ²⁶⁹

This view is shared by professionals:

"Most people want to be as independent as possible and influence their own destiny, instead of feeling helpless and sidelined." ²⁷⁰

From the Inquiry's first report, older people said that participation in society, good relationships, and good physical health through exercise and diet were important for their mental health and well-being. This section presents evidence from older people with mental health problems about what is important to them, drawn from a range of published and unpublished sources.

Current Government policy encourages individuals to take greater responsibility for their own health and well-being. Self-directed support is seen as a way to give people more control over the social services they receive, providing a 'tailor-made' service where possible. Examples of self-directed support schemes include direct payments in the UK and individual budgets in England, where service users are given a budget to purchase the services and support they would like for themselves. Direct payments and individual budgets have been piloted with older people but not as widely with people with mental health problems, and even less so with older people with mental health problems.

These approaches to self-directed support are consistent with the principles of recovery in mental health which stems from the belief that people with mental health problems can and should be supported and empowered to rebuild their lives in a way that helps them to achieve fulfilment and meaning, as defined by the person him or herself.

Recovery is not a word often used in the context of older people's mental health, perhaps because older people's mental health is most often associated with dementia, from which recovery in a formal sense does not mean cure. Rather, emphasis is on learning to live *with* mental health problems and maximising quality of life.

5.2 Meaningful activity

Participation in meaningful activity helps maintain well-being for older people, including older people with mental health problems. Older people want to make contributions to society and be recognised for them. A sense of purpose is crucial.²⁷² Activities and interests vary and preferences must be explored with individuals; they may include employment, volunteering, lifelong learning and individual hobbies. There is strong evidence for the contribution of physical activity to mental health and well-being.²⁷³

For some older people with mental health problems, keeping busy is a strategy for coping:

"Use it or lose it! I work myself to the bone, and it works for me. Seven years on [from being diagnosed] I'm still living with dementia, not dying from it."²⁷⁴

Others draw out the importance of the social aspect:

"When my husband died, I was lost... I had no structure to my life. I felt as though I was short of a goal in life.... Volunteering saved my life Having a purpose in life dragged me out of the swamp and onto the road again. And I've met some lovely people. It makes me shudder to think of the waste of my life if I hadn't got anything like this to do."²⁷⁵

Opportunities and support to keep busy with a range of activities, and to stay involved in community life, are crucial. Barriers to participation in employment, education and volunteering, due to discrimination against older people and discrimination against people with mental health problems, must be removed. The removal of conventional age barriers is important for people who have had unconventional life patterns. Unpaid carers who had to give up employment are one such group:

"My mother had Alzheimer's and I loved her dearly and I cared for her. When she had to be taken into care I was devastated. After she died four years ago I tried everything to get a job short of begging. No dice. They didn't want to know. There is still age intolerance. This has to change... Now the whole day is a struggle. I read. I walk. I take part in a church choir. But I am depressed. I am a 76-year-old lonely woman with nothing constructive to do!"276

The removal of age barriers may be especially important for people who have grown older with mental health problems and who may not have been able to work or engage in other activity for most of their adult lives. Several older people with mental health problems expressed a desire to make up for the time they feel they lost to mental illness:

"I spent years in and out of hospital because of my bipolar... it has finally settled down and I feel like I've just begun my youthfulness, I've just begun my life. I don't feel like I've had my life... I'm just starting to build it. I feel like I can be of use to the world now! It's lovely when you can find you can be of use."277

Support may be needed to enable participation of older people with mental health problems in meaningful activities, for example if older people have difficulty communicating and being understood, due to vision and hearing impairments or dementia. Wider issues such as transport and accessibility must be addressed for older people with limited mobility.

Sandwell Third Age Arts: Tackling depression through the arts

Sandwell Third Age Arts (STAA) provides creative opportunities for older people with mental health problems and their carers. Activities range from music and dance to painting, textiles and pottery. Trained artists run individual sessions in people's homes as well as group sessions in the community, hospitals or day centre settings.

STAA has been shown to help people maintain good mental health and alleviate symptoms of depression:

"It lifts you out of depression, you have to keep your mind busy"

For more information, contact Sharon Baker, Tel: 0121 500 1259, Email: info@staa.org.uk, or visit www.staa.org.uk

5.3 Support from friends, family and others

Social support from friends, family and neighbours can help older people with mental health problems to recover from stressful life events²⁷⁸ and maintain 'life as usual'.²⁷⁹ Many older people do not seek help from formal services when they are feeling distressed; two-thirds of older people with depression have never discussed it with their GP.²⁸⁰

Friends and family are often the first and only port of call. They play an important role in preventing problems from developing or getting worse:

"Before I retired I was in a deep depression but with my wife's help I recovered."²⁸¹

Being able to get out and see friends, or have them come to visit, is critical. One aspect of this is reassurance that loved ones are watching out for them. Older people with mental health problems worry about not being aware of deteriorating mental health. With support from others, early signs of distress may be noticed and acted on.

"One of the main reasons that I do so well is that I know I have my family behind me... I know that if anything should happen, if I was frightened or something, that all I would have to do is call." 282

Friends, family and neighbours also help out with practical tasks, which can help minimise everyday difficulties which are a risk factor for depression:

"My neighbours help me with things like changing light bulbs and putting out the bin."283

Peer support from people who have had similar experiences is particularly important. Older people with mental health problems value reciprocity and the opportunity to help others. Peer support can provide a social network and decrease the sense of stigma and isolation associated with mental health problems, for older people and their carers.

"Talking to people who understand helps more than anything."284

Peer support is recognised as valuable within 'adult' mental health services. It needs to be developed further as a model for older people.

However, not all relationships are good for mental health and well-being. Family can have a very negative effect²⁸⁵. Some family members may hold unsympathetic attitudes towards mental health problems. Lack of understanding can be damaging to relationships, leading to intense feelings of isolation and loneliness for older people with mental health problems.

"Relationships suffer if a partner doesn't understand about your mental health problem." 286

As noted in the Inquiry's first report, some BME older people feel very neglected by their families. Older lesbians, gay men and bisexuals also say that family can have a negative impact on their mental health; indeed, they are twice as likely to turn to friends than to family for emotional and other support.²⁸⁷

Elder abuse is most commonly perpetrated by a spouse or partner or other family members.²⁸⁸ Relationships that involve histories of domestic violence are damaging to mental health.

Not all older people have friends or family to turn to for help. Older people and people with mental health problems are seen as the most isolated groups in society, more than people with physical health problems, ex-offenders, homeless people and asylum seekers. Nearly four-fifths (79 per cent) of older people with schizophrenia are isolated. Social isolation is a risk factor for poor mental health and can also inhibit recovery for older people with mental health problems.

5.4 Information

People need information that is relevant, accessible and timely to help them make informed choices and plan for the future. Older people with mental health problems may need support to exercise their right to make informed choices for themselves.

Relevant Information needs to be appropriate to the mental health problem and from a trusted source. It must be positive, yet realistic, reliable, clear, practical and thus able to help people to consider their options. Information about implications for the future, for example of a diagnosis of dementia, is particularly needed.

Accessible Information needs to be provided in a range of formats, including written and oral, and in the right language for the intended audience.

Timely Information needs to be provided at an early enough stage to be useful. It cannot be dependent on time of diagnosis because less than half of older people with depression or dementia ever receive a diagnosis. Public information services in the media are therefore essential if information is to be useful to the population at large.

Co-ordinated Information needs to be co-ordinated across different services and provided at an early enough stage to be useful.

5.5 Advocacy

Advocacy services are important for enabling vulnerable people, including older people with mental health problems, to exercise their right to make choices for themselves. Advocates can support older people to be involved in decision-making.

Older people say they would like someone to 'fight their battles':

"When you're on your own you have no one to fight your battles for you and they don't take any notice of you, what you say. That is the most frustrating thing that I came across. They look at you like you're there already, like you're daft." 292

While older people did not use the term 'advocate', they did describe the important elements of a person who could be caring and understanding and be supportive.

"Anyone, it could be a cousin, or a selfless person who hasn't got anything else to do, or a social worker." 293

The need and demand for advocacy services will rise as the number of older people with mental health problems increases. Advocacy is recognised as a significant area for service development and future research.²⁹⁴

Age Concern Mental Health Advocacy Project: Training volunteers to advocate for older people with mental health problems

This three-year project is working to develop a new volunteer advocacy service for older people with mental health problems. Four pilot sites have been selected to test this service. It is envisioned that older people will play an active and central role in providing advocacy to their peers on mental capacity and mental health and well being issues.

For more information, contact Neil Mapes, Project Co-ordinator, Tel: 07767 693357, Email: neil.mapes@ace.org.uk, or visit www.ageconcern.org.uk

5.6 Support for unpaid carers

Friends and family provide the bulk of care, emotional and physical, for older people with mental health problems. Given the major role that they play, it is crucial that unpaid carers are adequately supported.

Many unpaid carers are themselves older and at risk of physical and mental health problems because of their caring responsibilities. They are also at higher risk of financial difficulty because of the direct costs of caring and the indirect costs of having to give up jobs. They often experience stress, depression and social isolation.²⁹⁵ Carers are often in crisis by the time they receive help.

Unpaid carers of older people with mental health problems want practical help that will enable them to do more than just survive. Help should be provided at an early stage to prevent problems from spiraling out of control.

"I have a friend up the road – they are a bit younger than me, in their middle 70s – and her husband's got terrible Alzheimer's, really ill. Now, she's had no sleep for weeks and weeks and weeks. He walks about at night, tries to go out at night and she's been struggling with this. She's had at least six or seven people come to see her, sit down and take all sorts of notes. Then they say, 'You need help, you shouldn't be doing this'. But nothing happens! Nothing at all. Now if someone came and said 'right' and took their coat off and said, 'I'll go upstairs and do the bedrooms for you or I'll empty that basket of ironing'... There's a lot more sense in that sort of practical help. Just now he's been taken really ill and when they got him to hospital, they told her he needs 24-hour care. But she'd have liked him at home with just a bit more help so she could have a night's sleep and then she could cope during the day."²⁹⁶

Carers also want:

- Information about mental health problems and the best way of caring
- Information about how to access support services such as respite and home care (see chapter 6)
- Advice about looking after their own health
- Support from people who understand and a sense of "being in it together"

"I need someone to talk to as I cannot talk to my husband [who has dementia] – I have lost my friend."297

Government policies acknowledge the crucial role that unpaid carers play in providing support to older people in their own homes. They recognise the need for a coordinated approach that gives all carers access to relevant information, ensures that mainstream services for older people take account of carers' needs and preferences, and gives a break to carers who are at serious risk of breakdown. Since the 1990s, successive legislative acts^{298, 299} and numerous strategies across the UK have been developed.

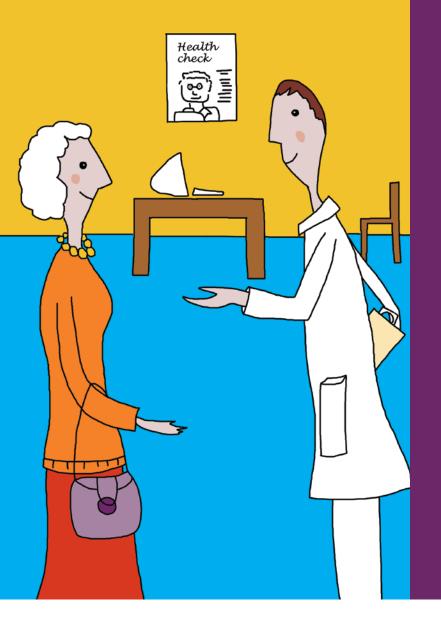
However, carers' expectations – and Government's aspirations for carers – are not being met.³⁰⁰ The present situation is not satisfactory for many.³⁰¹

It is important to identify carers at an early stage and involve them in the assessment and planning for the people they care for. Plans should take account of the impact of cultural differences and same-sex relationships and the potential for abuse by carers. Assessments for carers are also required, in order to identify their needs and examine their future options.

5.7 Making a difference

What can be done to enable older people with mental health problems, and their carers, to help themselves and each other?

- Listen to what older people with mental health problems and carers say.
- Recognise their capacity for helping themselves and each other.
- Provide opportunities for participation in meaningful activity and social engagement.
- Develop peer support for older people with mental health problems.
- Develop information and adviocacy services for older people with mental health problems.
- Support organisations that are already delivering these services.
- Integrate informal resources with formal service provision and develop innovative ways for older people to develop and draw on their own resources.
- Develop an understanding of recovery for mental health problems in later life.



Chapter 6 Improving current services

Key points

- Mental health problems in older people are under-diagnosed and under-treated in housing, health and social care.
- The provision of services as the number of older people with mental health problems grows will be a major challenge.

Adequate and timely provision of high quality services can dramatically improve the lives of older people with mental health problems. However, current services often do not meet or even recognise the needs of older people with mental health problems.

This chapter considers the state of current services and looks at how they could be improved, focusing on six areas: housing, primary care, social care, specialist mental health services, acute hospitals and care homes.

6.1 Current perspectives on services

6.1.1 Evidence from older people

Older people with mental health problems are very clear about the kind of services they would like to receive. They want a range of options for 'help that fits the person', which is fast, flexible, practical, consistent and dependable. They want help to be available when they need it, including in the evenings and at weekends. They also want help that reaches out to them:

"Someone to come round and support me when I am having a bad period."305

Older people with mental health problems value services that make them feel safe, understood and respected, where members of staff are familiar, knowledgeable and trustworthy. Support from people who can 'help fight [my] battles' is key.

Older people with mental health problems say that services seem to be more sensitive to mental health issues now than they were 10 years ago:

"At least now they are prepared to admit that my wife has emotional problems and give us some help and some respite for me. When it began....mental illness was not even acknowledged."306

However, many older people still lack the help and support they need. Services appear fragmented and not well connected to the communities they serve. Specialist mental health services are particularly remote. Services seem to lack knowledge and understanding of:

- The history of local communities, for example the impact of the 'Troubles' in Northern Ireland
- The range of informal resources that exist in the community such as local networks and voluntary organisations
- Wider changes taking place in the community that may impact on older people's mental health; for example the arrival of newly retired people on relationships within the community, as long-time residents adjust to their changing environment while new residents struggle to develop social networks.

Older people say that it can be difficult to know what is available in their local area, and even more difficult to understand how services fit together. A study of the views of older people with mental health problems completed for the Inquiry found that:

"It [is] not clear how the contributions of smaller, community projects and networks [are] seen or placed within the whole system of care, especially by more specialist services and staff. This is important because it is these smaller, more intimate and familiar types of support that both older people and carers identified as central to their ongoing well-being and sense of connectedness." 307

6.1.2 Evidence from other sources

Current Government policies for older people's mental health promote access to integrated services that span health and social care, primary and specialist care, physical and mental health care, and community and hospital settings. Emphasis is placed on early detection of problems in primary care, access to specialist services including comprehensive multidisciplinary teams, and support for unpaid carers.

Numerous inspectorate reports have examined the state of mental health services for older people in the UK. While at least one review found evidence of 'excellent, innovative, user focused services for older people', 308 the findings of the Audit Commission's *Forget Me Not* report of services in England and Wales (2000) are more typical:

"Wide variation in practice, in the kinds of resources that were available, how effectively the agencies worked together, what carers felt about their local services and how commissioners were able to shape the pattern of provision. Older people and their carers have often not received the help they need, when they need it." 309

Six years later, an authoritative review of older people's services, *Living Well in Later Life* (2006), concluded that:

"All aspects of mental health services for older people need to improve." 310

Commissioners play a crucial role in shaping local services. Inspectors and regulators play an equally important role in driving service improvements.

6.2 Housing

Good housing is basic to mental health and well-being and can play an important role in improving the well-being of older people with mental health problems,³¹¹ but it is often overlooked in discussions of services for this group. A third of all households in the UK are headed by a person aged 60 and over and most people want to continue living in their own homes as they grow older.³¹²

Older people with mental health problems, like other older people, have a range of housing needs. A key priority for housing providers is to develop a range of options that can accommodate these diverse and changing needs. For example, older people with mild depression, older people with dementia and people who have grown older with long-term mental health problems (who may have spent long periods in mental hospitals) all have different needs.

Housing strategies for older people, like the forthcoming National Strategy for Housing in an Ageing Society in England, must recognise the role that housing plays in supporting older people with mental health problems. Strategies must also ensure that all new housing meets quality standards for the long-term needs of the population, including homes that can be lived in for an entire lifetime, and that existing housing is improved to meet these standards.

The main factors relating to housing are the quality of the housing and the support received within the home, together with general matters such as location, suitability, warmth, security and links with the wider community. Repairs, improvements and adaptations are often needed to maintain quality. Support may be provided by home care services (see Section 6.4) or in specialist housing such as sheltered and extra care housing.

Specialist housing options such as sheltered and extra care housing have developed over the years to meet the needs of older people. Specialist housing can have a positive impact on mental health and well-being in later life, for example by preventing isolation and depression among older people.³¹³ It can also offer a supportive environment for people with dementia, especially when there are good links with local health and social care services.³¹⁴ Studies suggest that group living environments with units of between eight and ten people enable people with dementia to see staff, contribute to domestic chores and feel relaxed and comfortable.³¹⁵ However, housing schemes must ensure that people with dementia and other mental health problems are not stigmatised by other residents. National shortages in provision must also be addressed.

Extra-care housing can enable people with dementia to live independently for nearly as long as those without cognitive impairment, and enable friends and relatives to remain part of the informal support network.³¹⁶

Oak House: Providing extra-care housing for older people with dementia

Oak House is a specialist housing scheme with 38 flats and an 'extra-care' cluster of nine flats for people with dementia. The scheme employs an activities co-ordinator and offers facilities such as lounges, a hair salon, a laundry, a guest room and assisted bathing with a Jacuzzi bath. Also available are freshly cooked lunches and day services three days a week, with one day reserved for people with special needs including people with dementia. The communal garden is designed to suit different moods and activities and incorporates a circuit for walking that discourages disorientation. District nurses are available and a local GP visits weekly. The scheme also has good links with the local mental health services.

For more information, contact Jane Minter, Housing 21, Tel: 0870 192 4512, Email: jane.minter@housing21.co.uk

Assistive technologies have developed to support older people, including older people with mental health problems, enabling them to feel safe and secure and to continue living in their own homes. They include monitoring options such as tele-health and tele-care and 'smart house' technologies such as sensors that can tell if someone has left their bed and verbal messaging units that remind residents to turn off taps or cookers. These technologies help support people with daily activities and can enhance unpaid carers' abilities to provide care, thereby reducing their own risk of developing mental health problems.³¹⁷ Government has invested in pilot sites. Further development of assistive technologies is needed, particularly for marginalised and excluded groups.

Internet technology can also help to reduce isolation and depression by enabling older people, especially those who are unable to get out and about, to develop and maintain contact with friends, family and others with similar interests.³¹⁸

Wider community engagement is important for mental health and well-being. Urban planning and design, for example of public spaces, can help to develop supportive communities that encourage rather than discourage participation by older people with mental health problems.

6.3 Primary care

Primary care services provided by GPs, nurses, pharmacists, optometrists, dentists and allied health professionals are the main community-based services used by older people.³¹⁹ The majority of older people with mental health problems who seek help initially go to their GPs. Most are treated within primary care and are never referred to specialist mental health services.³²⁰ As the first and often only point of contact within the health care system, GPs have an enormous responsibility to correctly identify and respond to older people's mental health needs. GPs also play a pivotal role in coordinating care across a range of services from prevention through to end-of-life care.

Early detection and diagnosis is important for enabling older people and their carers to make decisions and plan for the future. Ninety per cent of GPs agree it is important to detect early signs of depression and make a diagnosis. They also express confidence in their ability to treat older people with depression, although they are less confident about diagnosing and treating dementia.³²¹

However, the reality is that mental health problems in older people are vastly under-diagnosed and under-treated. Only half of older people are treated for depression and less than half of older people with dementia are diagnosed by GPs.³²² Alcohol and drug misuse problems are also often missed, even though older people respond just as well to treatment as younger people.³²³ Older people with sensory impairments, older men and older people with lower levels of educational attainment are most at risk of having their mental health needs overlooked.³²⁴

The mismatch between what GPs believe they do and what they actually do to detect and diagnose mental health problems in later life is disturbing, especially given the high rates of suicide among older people. There are several contributing causes for these deficiencies:

■ Patient barriers. Older people (and their families) may not recognise their distress as a problem that GPs can do anything about, or they may dismiss it as a 'normal' part of ageing. Some do not raise it because of the stigma attached to mental illness or because they do not think it is appropriate to mention mental health problems during medical consultations.³²⁵ Different cultural understandings of mental health and illness can also play a part.³²⁶ Others feel that their GPs do not take them seriously, dismissing their concerns and telling them to just 'pull themselves together':

"I think a sympathetic and understanding GP and somebody who knows you well is very important. Because it's that first contact that is vital really. If [the GP] says, 'Oh pull yourself together, get on with it, live your life'... If you get that sort of reaction I can imagine being very much put off." 327

Public education of individuals and their families can overcome these patient barriers by teaching them to recognise the symptoms of depression, know that it is treatable and know where to seek help. Direct access to specialist mental health care through helplines, support groups and therapy centres may be another way of overcoming these barriers:

"There should be somewhere that a person with depression can go for this first stage of consultation." 328

- **Provider barriers.** GPs may lack the skills to make a correct diagnosis of mental health problems in older people. Older people often have multiple physical and mental health problems with similar or overlapping symptoms.³²⁹ Older people are also more likely to report only their physical symptoms.
 - Ageist attitudes may lead GPs to assume that symptoms such as low mood or memory loss are a 'normal' or 'understandable' part of ageing.³³⁰ They may erroneously believe that there is not much that can be done anyway. Lack of available treatments and lack of information about local resources are also barriers.
 - GPs need better education and training. Support from mental health specialists, through joint working arrangements, can be effective although it is not always available. Incentives to detect and diagnose problems, for example the Quality and Outcomes Framework, have proved effective.
- **Systemic barriers.** GP appointments may be too short to allow for proper exploration of mental health problems. Perceived or actual lack of treatment options may inhibit GPs from making a diagnosis. Wider reform of the health care system is needed to address these problems.

Response and treatment may still be inadequate even when problems are recognised and diagnosed.³³¹ Often, the only treatment offered for depression is medication. Older people are rarely offered **psychological therapies**,³³² despite abundant evidence that they are just as effective as antidepressants for older people, with the added advantage of not interacting with other medications.³³³ Psychological therapies are just as effective for older people, who most commonly suffer from minor or sub-threshold depression, as they are for younger people, who are more likely to have major depression.³³⁴ Older people value psychological therapies as effective and empowering.³³⁵ One study reported that 57 per cent of older people, especially women, preferred therapy and counselling to medication.³³⁶

Psychological treatment should therefore be considered a first option in treating depression in older people.³³⁷ However, evidence shows that it is not. Some older people have no choice but to take anti-depressants.³³⁸

"I had a doctor who would already be writing the prescription as I walked into his office. There was never any mention of therapy.339"

"I went to my doctor and he suggested Prozac. I told him no medication, especially Prozac. He's a nice enough guy usually, but when I said I just wanted to talk to someone, he totally patronised me.³⁴⁰"

Older people were left out of early Government pilot projects to increase access to psychological therapies. This neglect appears to have been rectified but developments must continually be monitored to ensure positive outcomes for older people. It is essential that new services that are developed (such as computerised cognitive behavioural therapy) do not indirectly discriminate against older people. For example, they must be appropriate to those with sensory impairments or those who lack IT skills.

Older people with mental health problems must have access to **other types of therapies** too.³⁴¹ Reminiscence, art, drama and music therapy are as effective as antidepressants in treating mild or moderate depression.³⁴² Exercise therapy is underprescribed for people of all ages. The availability of tailored exercise programmes would help improve primary care services for older people with mental health problems.³⁴³

Collaboration with mental health specialists is associated with better outcomes for older people with mental health problems. Older people with major depression whose GPs teamed up with depression care managers were nearly 50 per cent less likely to die within five years than those whose care did not involve depression care managers. Various models of joint working have been developed including regular formal meetings between primary and secondary care staff; mental health clinics held in primary care; and community mental health team nurses linked with specific GP practices.

Given the broad scale of depression in later life, with a quarter of older people experiencing symptoms, it is clear that the answer does not lie solely in providing 'medical' treatments. Wider public health, social inclusion and community development approaches are required. GPs, nurses, pharmacists and others can play an important role in signposting older people with mental health problems to other community resources, and encouraging older people to manage their own illnesses, as this has been shown to have positive outcomes for treatment and a positive impact on mental health and well-being in later life.

Rushey Green Time Bank: Tackling depression by referring patients to community resources

Time banking promotes the exchange of practical help and support between members of a local community. Participants 'deposit' time, rather than money, in a Time Bank by providing practical help and support to others. They are then able to 'withdraw' their time when they need help themselves. Time bank brokers match up 'givers' and 'receivers'. All types of help and support are recognised, ranging from house cleaning to accompanying people on walks to teaching language lessons.

Rushey Green Time Bank is based in a GP practice with approximately 130 members of all ages, half of whom are aged 50 and over, some of whom are older people recovering from mental health problems. It was started in 2000 by a GP who was convinced that many of his patients who had symptoms of depression and isolation could be helped by increasing their social contacts and finding a way for them to feel needed by others and useful to society. Feedback from members indicates that time banking has reduced social isolation and improved mental health and well-being.

For more information, contact Maria Meska, Tel: 020 7138 1785, Email: rusheygreen@londontimebank.org.uk, or visit www.timebanks.co.uk

6.4 Social care

Social care is defined as 'the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relationships'.³⁴⁷ Three-quarters of social care service users are older and a high percentage of them have mental health problems.³⁴⁸ The provision of social care as the number of older people with mental health problems grows will be a major challenge.

Innovations such as direct payments and individual budgets fulfil social care's aims of enhancing choice and control for service users and enabling them to lead meaningful lives. To date however, these innovations have not been applied to older people with mental health problems. Social care has limited resources and is perceived to be fragmented, not well understood by the public, lacking in confidence and lacking an identity. Tightening eligibility criteria mean that services are being concentrated on fewer people with more acute needs, even though policy emphasis is on prevention. Funding remains the most difficult issue, as more older and disabled people have to find and pay for their own private care or else rely on family members or friends.

Age discrimination in social care is a significant problem for older people with mental health problems (see Chapter 3). The current system, which withdraws services from users once they reach 65, must be reviewed urgently.

This section focuses on home care, day services and respite care. Residential care is covered in Section 6.7.

Home (domiciliary) care is essential to enabling older people to stay at home and take part in their communities. Home care can enhance independence, provide opportunities for social interaction and reduce isolation in older people with mental health problems including dementia.³⁵¹ Home care can also benefit unpaid carers, who are often highly stressed and at risk of developing mental health problems.

To be successful, home care workers must have sufficient time to develop trusting relationships with the people they care for. They must be trained to recognise and respond to late life mental heath problems.³⁵² Services must be organised to respond sensitively to people's needs, and eligibility criteria must be flexible enough to extend services to the many people who are not currently eligible but would certainly benefit.³⁵³

The nature of the work and low levels of pay and status lead to difficulties recruiting and retaining good quality home care staff. Wider workforce planning is needed to ensure the availability of workers (see Chapter 7).

Home Care Plus: Providing flexible care and support to people with dementia

Home Care Plus provides intensive one-to-one flexible care and support to people with dementia on a frequent, often daily, basis. Staff provide support to help clients pursue interests and take part in meaningful activities at home and in the community. They escort people to health appointments and assist with visits with friends and family. They provide practical support and personal care, and promote emotional well-being. The type of support and care varies according to the needs and wishes of the client. An independent evaluation has found positive impact on the lives of clients and staff.

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Day services include lunch clubs, drop-in centres, befriending schemes and other social groups for older people with mental health problems. Day care has been shown to delay institutionalisation for older people with dementia.³⁵⁴ Better understanding of the effects of day care on older people with other mental health problems is needed. The range of interventions provided in day care settings must be increased to meet older people's varied needs.

Respite care encompasses a range of services – including family placement schemes, sitting services, befriending, day care, and short stays in different types of residential settings – that provide breaks to enable unpaid carers to continue in their caring roles. Services vary in the length of the breaks, where they are provided (at home or in institutions) and the level of care offered.

Respite care has been found to improve quality of life and to reduce depression in unpaid carers of older people, but evidence is mixed for unpaid carers of older people with dementia. Respite is often provided too late, when unpaid carers have already reached a state of crisis. To improve, respite care must be provided at an earlier stage. Services must be flexible to meet a wide range of needs, which change over

time. Services must also aim to maintain and support the relationship between the unpaid carer and the person being cared for.

Reviews of respite care have tended to focus on unpaid carers of older people with dementia.³⁵⁷ Better understanding of the effects of respite on older people with dementia themselves is needed. Also needed is better understanding of respite services for unpaid carers of older people with mental health problems other than dementia.³⁵⁸

6.5 Specialist mental health services

Relatively small numbers of older people with mental health problems see specialist mental health professionals. Fewer than 10 per cent of older people with clinical depression are referred,³⁵⁹ compared with about 50 per cent of younger adults with mental and emotional problems.³⁶⁰ Older people with mental health problems who do receive specialist care report mixed experiences.

Inpatient mental health services are necessary when symptoms of mental health problems become acute. Between 30 and 50 per cent of inpatients in psychiatric hospitals and facilities are aged 65 and over.³⁶¹ Some older people describe inpatient care as a haven offering respite and relief, where they know they will be taken care of:

"I feel protected and safe when I am in hospital; you know that they are going to help you." 362

Others describe inpatient care as a prison where they lack control over their own lives. Some older people described being given electro-convulsive therapy (ECT) without being told:

"I would never have [ECT] again. They say that your memory will come back, but it doesn't, not ever. Nobody sat and told me why they were doing it, why they were going down that route for treatment. They don't explain the clinical process to you. It is terrifying."363

The provision of separate inpatient beds for older people with dementia and those with other mental health problems like depression or schizophrenia is considered good practice, 364 although in reality the distinction is not usually clear or absolute.

Mental health wards for older patients are less clean, more noisy and more violent than average. The Rowan Ward investigation of abuse by care staff (2003) identified geographical isolation, low staffing levels, lack of training, lack of nursing leadership and lack of clinical governance as key risk factors for poor quality services. Staff on mental health wards often lack confidence in treating physical health problems, which may be significant and complex for older people. More effective liaison between

medical and psychiatric services is needed. Workforce education and training issues are addressed in Chapter 7.

Other specialist services developed to prevent admission to inpatient care include assertive outreach, crisis resolution and early intervention teams targeted at people with severe mental health problems. These services have been developed primarily for 'working age adults'. They must be extended to include older people.

6.6 Acute hospitals

Older people are the main users of acute hospital services and up to 60 per cent experience mental health problems – most commonly delirium, depression and dementia – during a stay in hospital.³⁶⁸ Admission to an acute hospital is often the first opportunity to diagnose and respond to mental health problems in older people. Yet all of the available evidence indicates that they are under-diagnosed, under-treated and poorly managed in acute care.

Most of the existing research has focused on delirium. As discussed in Chapter 4, routine screening and assessment can prevent delirium from developing in hospital settings. Healthcare systems and services often unintentionally stimulate or aggravate delirium in older people. The safest clinical approach to dealing with delirium is to assume that all older people presenting with confusion have delirium until proved otherwise. All clinical encounters with older people should therefore include a routine assessment of cognition.

Extensive **education and training** at all levels is needed to enable hospital staff to recognise mental health needs in older people. The majority of staff who care for older people in acute hospitals have little or no understanding of older people's mental health needs and feel unable to respond appropriately.³⁶⁹ Staff often fail to distinguish between delirium and dementia³⁷⁰ and other mental health problems that may occur together. Education and training needs are discussed in more detail in Chapter 7.

The development of **liaison mental health services** is one way to improve skills, attitudes and knowledge about mental health problems for general care staff.³⁷¹ Liaison mental health practitioners are multidisciplinary mental health specialists (psychiatrists, nurses, occupational therapists and others) who work collaboratively with general care teams in acute hospitals. They aim to integrate physical and mental health care and overcome entrenched divisions between medical and psychiatric services.³⁷²

Liaison professionals provide education and training as well as rapid access to a specialist mental health team to assist with the management of severe and complex cases. They also promote routine assessment of all people admitted to hospital, and even act as advocates for older people with mental health problems. They differ from consultants in that they provide a rapid response service, and proactively seek to work with medical colleagues to develop better standards of mental health practice in general hospitals. The Royal College of Psychiatrists has identified liaison services as the preferred model for working with a moderate or large general hospital.³⁷³

Adjustments to the **hospital environment** can reduce distress for older people with mental health problems. Adaptations that can promote mobility and orientation include improved lighting, reduced noise, carpeting, raised toilet seats, low beds, clocks, calendars and pictorial guides. The introduction of more flexible care procedures has also been shown to improve outcomes for older people with mental health problems.

Further research is needed on the diagnosis, treatment and management of depression, dementia and other mental health problems such as alcohol and drug misuse in acute hospital settings.

6.7 Care homes

The majority of older people in care homes have mental health problems so the provision of high quality mental health care in this setting is vital. Between 50 and 80 percent of residents have dementia, 40 per cent have depression and a high percentage have both. Care home residents include older people with long-term mental health problems like schizophrenia who 'graduated' from long-stay hospitals when they closed. Delirium, alcohol and drug misuse also affect older people in care homes.

However, many mental health problems are not detected, diagnosed or treated in care homes. The barriers are similar to those described in Section 6.3. In care homes there are the added barriers of low expectations and complex health problems because of the high levels of physical illness and frailty in the resident population.

Moving into a care home can be a major life transition that involves considerable losses, increasing the risk of mental health problems. Depression appears to be more common among older people who have recently moved into a care home, compared with those who have been living in a care home for some time.³⁷⁴ Assessment of mental health needs prior to admission may be able to help detect problems early on.

Quality of life in care homes is influenced by a range of factors including retaining a sense of personal identity, feeling part of a wider community and having opportunities for meaningful activity.³⁷⁵ Mental health may be a more important factor than physical health. For example, quality of life for care home residents with dementia is more closely linked to whether they have depression and anxiety than to their physical disability.³⁷⁶

Another key determinant of quality of life is the quality of **relationships between residents and care home staff**, who are often much younger than residents and increasingly from different cultures. Cross-cultural education and training, particularly around concepts of mental health and well-being, is needed and will become even more important in the future as care home residents and staff become more diverse.

Relationships in care homes are often disrupted and **bereavement** can lead to depression. Older people living in care homes must cope with fellow residents passing away on a regular basis. This may entail the loss of visits from the residents' families.

Older people living in care homes must also cope with the departure of care home staff on a regular basis, due to high turnover in the sector. Attention is being paid to end-oflife care in various settings, but a focus on wider bereavement issues is needed.

Care home staff are often under-trained, overwhelmed and generally not well supported to identify and respond to older people's mental health needs. **Education and training** can lead to increased rates of detection of depression, more treatment and better outcomes for older care home residents.³⁷⁷ Education and training is discussed in more detail in Chapter 7.

Clinical leadership within care homes is needed but often lacking. One survey of care homes found that 20 per cent had no regular GP visits.³⁷⁸ Access to specialist services such as psychological therapies and mental health advocacy is often not available in care homes.

'In-reach' by primary care providers and mental health specialists can provide much needed support to care home staff to ensure that mental health problems are diagnosed and treated, and that physical health problems, which can contribute to poor mental health, are also addressed. One effective model is liaison-style support from specialist mental health services with a strong educational component for care home staff, including guidelines and supervision. Similarly, liaison services can link between hospitals and care homes to facilitate the discharge process.³⁷⁹ Support from mental health specialists improves the identification of depression and dementia, resulting in better outcomes for residents.³⁸⁰

'In-reach' services that are matched with support in the care home that is focused on the individual resident's needs and wishes have been found to be effective.³⁸¹

North Yorkshire and York Primary Care Trust: Providing individualised care to reduce depression in older people in residential care

As part of an eight-week programme, care home staff received four training sessions on depression and older people and weekly one-to-one mentoring sessions with a community psychiatric nurse or an occupational therapist.

Care staff then worked individually with depressed residents, starting with interviews to find out what matters most to them. Staff worked with each resident to identify three specific life improvements and a plan for achieving them. Goals included re-establishing contact with friends or relatives, resuming a hobby and resuming religious activities.

Residents who received the intervention showed significant improvements compared with a control group who did not receive the extra help. Care staff also felt empowered. The approach worked for all residents except those with severe dementia. The findings may be applied to other services and settings such as home care and sheltered housing.

For more information, contact Dr Jake Lyne, Tel: 01904 725725, Email: jake.lyne@nyypct.nhs.uk, or visit www.well-beingandchoice.org.uk/reducingdepression.htm

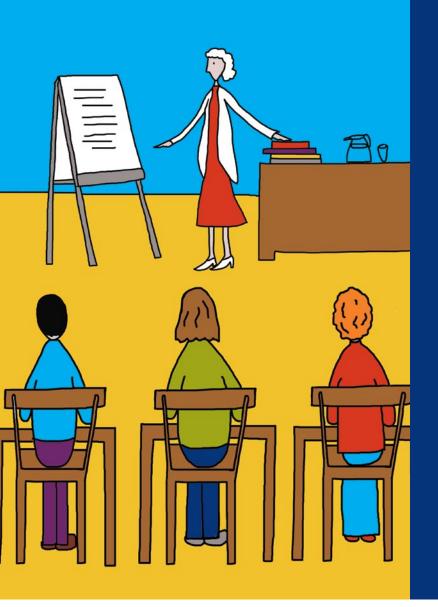
Care home managers play a crucial role in providing leadership and setting the tone and culture of the care home.

Given that mental health problems in care homes are so common as to be nearly universal, many improvements will depend on **reform of the whole organisation or system**, rather than just the action of individual care home staff.³⁸² Low wages for care home staff may lead to high turnover and low morale and must be addressed. Staff shortages which mean that care home staff are not able to spend enough time with residents to recognise changes in mood or behaviour that may indicate depression, must also be addressed. Standards that will drive improvement of the whole care home must be developed and implemented in the assessment of care services.

6.8 Making a difference

What can be done to improve current services?

- Develop interventions at the individual and systemic levels.
- Promote collaborative working with mental health specialists.
- Pay more attention to the role of housing support.
- Develop incentives for GPs to detect and diagnose late life mental health problems.
- Ensure that older people have access to psychological therapies.
- Develop home care services for older people with mental health problems.
- Develop liaison mental health services in acute hospitals and care homes.
- Introduce routine screening and assessment of delirium upon admission to acute hospitals and of depression upon admission to care homes.
- Pay more attention to bereavement in care homes.
- Influence commissioners and inspection and regulatory bodies.
- Educate and train staff in all settings (see Chapter 7).



Chapter 7 Facilitating change

Key points

- Workforce development, education and training is needed to ensure that skills are matched to the current and anticipated needs of the population.
- Strong leadership is crucial to making change happen and it is needed at many levels.

Chapters 3-6 have highlighted the need for change and identified actions to improve services and support for older people with mental health problems. Support is needed to make change happen.

This chapter focuses on five aspects of support for change: workforce development; workforce education and training; capacity building and support; investment; and leadership.

7.1 Current perspectives on change

This report is written at a time of considerable change. Across the UK, new governments are setting new priorities, and the Comprehensive Spending Review (CSR), to be announced in Autumn 2007, will set spending priorities for the next three years. The older population is diverse and constantly changing. The first wave of 'baby boomers' has reached 65 with higher expectations than previous generations. The generations that will follow are expected to bring with them even more varied expectations and challenges for public services and for society in general. Rapid growth in the black and minority ethnic (BME) older population will have an impact, as will the increasing numbers of people with experience of mental health problems.

There is a strong push to devolve power from central government to local government and on to local communities and individuals, with the NHS and local government increasingly working together, particularly in relation to the promotion of well-being. Innovative ways of stimulating greater civic involvement and participation are being sought. Social enterprises aim to bring together the benefits of the public and private sectors. The 'third' sector, made up of voluntary organisations and charities, is being encouraged to play a growing role in service provision.

Services are being restructured to make them more personalised and to better meet the needs of the people who use them. In Northern Ireland, following the Review of Public Administration, a major restructuring of public services is underway, with implications for local government, education, health and social services. Elsewhere, organisational restructuring and financial pressures within the NHS have led to cuts in staff levels and services, resulting in instability. Social care is frequently described as being in a state of crisis, and the need for a settlement on long-term care funding is increasingly apparent. New developments in self-directed support, such as the extension of direct payments and individual budgets to more vulnerable groups of people, give an indication of what the next generation of public services might look like.

These changes have the potential for exciting improvements, but the force and pace of change has created uncertainty and anxiety which may, paradoxically, inhibit further change. A big part of the problem is that much of this change is seen as coming from above. At the service level, constant change makes it difficult for organisations to plan for a sustainable future. This is a situation in which small voluntary organisations often find themselves, with certainty about funding only for the coming year. At an individual level, many workers are concerned about the implications for their jobs – whether they will still have jobs, how their responsibilities will change and how they will be expected to work with others in their new roles.

More attention and support must be provided to ensure that the process of change does not corrupt its aims. There is no indication that reform will come to an end, nor would that necessarily be desirable. However, reform needs to be handled with sensitivity to the needs of those most closely involved in the provision of new services.

7.2 Workforce development

A key concern is whether there will be enough of the right kind of workers to provide the services and support that older people with mental health problems will need in the future. Despite advances in technology, the provision of high quality services and support will continue to rely on people to deliver them. If there are too few people, the development and delivery of high quality services and support to older people with mental health problems will be impossible. Service providers will be required to cut services and whole professions may be at risk of disappearing. There are already difficulties in the recruitment and retention of social care workers which prejudice the quality of care provided.³⁸⁴

There is a risk of future workforce shortages, as the number of older people with mental health problems dramatically increases and the number of 'working age' people falls. In the UK, it is possible that the prevalence of mental health problems will increase, further reducing the number of 'economically active' people. Increasing pressure on friends and family to provide unpaid care may also hamper labour market growth.

Workforce shortages will lead to increased competition for labour, with potentially severe consequences for professions like social care, which suffer from low pay and low status for extremely challenging work. Dramatic improvements in pay, status, working conditions and opportunities for advancement are needed to attract workers into the caring professions. Wider campaigns to give social care a professional identity and to elevate its status are also needed. If these improvements cannot be made and professions do not attract enough workers, the result will be reduced quality and even greater gaps in provision. 385

It is not clear who will fill these gaps. Possible approaches include:

- Increasing the in-flow of immigrant workers
- Extending people's working lives and changing the definition of 'working age'
- Increasing skills training
- Providing psychological therapies to people with depression and anxiety to enable them to recover and return to work.

None of these approaches can be easily and swiftly implemented, and some are, in global terms, inappropriate.

The workforce of the future may look different to the one we have now. New types of mental health workers have been recruited and trained to work with adults aged 18 to 65; examples include Support, Time and Recovery (STaR) workers and Community Development Workers to work with BME communities. These workers must be trained to work with older people.

In the long-term, self-directed support measures such as direct payments and individual budgets can be expected to shape the development of new markets, as users demand different services from those currently on offer. These measures have not yet been applied to older people with mental health problems. Better understanding is needed of the services and support they might want so that markets can be developed for them.

The NHS and others should devise or revisit and implement strategies for recruiting the staff they will need to cope with the anticipated demand for services for older people with mental health problems.

7.3 Workforce education and training

Many of the suggestions for ways to improve current services point to the need for improved education and training for professionals and other frontline workers (see Chapter 6). All staff working in health, social care and housing should be educated and trained to recognise older people's mental health needs and respond appropriately, in culturally sensitive ways and in accordance with nationally defined standards of knowledge, skills, attitudes and competencies. Education and training is especially important for staff in acute hospitals and in care homes, where the majority of older people experience mental health problems.

Older people's mental health is currently a gap in most basic and continuing education. Few curricula include modules on older people or mental health, with even fewer on

older people's mental health. Only two per cent of primary care practice nurses have received any mental health training.³⁸⁶ In surveys conducted in 2000 and 2002, less than half of GPs felt they had received sufficient training to help them diagnose and manage dementia;³⁸⁷ in a 2006 survey, only 31 per cent felt they had had enough training.³⁸⁸ Only 12 per cent of home care workers who care for a person with dementia have received training in dementia in the previous three years.³⁸⁹

Training must be provided to all staff who work with older people to ensure that older people's emotional as well as their physical needs are met. Skills in recognising and responding to common late life mental health problems must be taught. Training should include the life stories of older people with mental health problems to create a better understanding of what constitutes high quality care and how quality of life can be maintained. Staff working in generic services must recognise that older people, many of whom will have mental health needs, are the main group they will be working with in the future.

Training should also emphasise multidisciplinary working among nursing, medical, occupational therapy, psychology, social work professionals. Collaborative working is a skill that can be developed. For accreditation, professionals should be required to demonstrate positive attitudes as well as competencies in caring for older people with mental health needs.

In acute hospitals, medical and psychiatric staff need cross-training to overcome the divide between physical and mental health domains. Some hospital nursing staff believe that caring for patients with mental health needs falls outside of their duties.³⁹⁰ Targeted education and training is needed to overcome these barriers.

Let's Respect: Improving nursing practice in acute hospitals by developing support and training materials

Let's Respect is a campaign aimed at better meeting the mental health needs of older people, focusing initially on generic secondary care settings and the three most common mental health problems – depression, delirium and dementia.

Let's Respect has produced a range of support and training materials for nurses working in acute hospitals including a good practice guide and PowerPoint presentations. A Resource Box toolkit uses powerful photographic images and case studies to provide practical suggestions for ways to better meet the mental health needs of older people in acute care settings. Information is presented in a variety of formats, including booklets, guide books and bookmarks.

For more information visit www.olderpeoplesmentalhealth.csip.org.uk/lets-respect.html

In care homes, training of staff can improve the detection of depression, resulting in more treatment and better outcomes for older care home residents.³⁹¹ Training must be aimed at qualified nursing staff as well as care home staff, since studies have shown that nursing staff are no more likely to recognise depression than non-nursing staff.³⁹² Training must offer more than just awareness-raising and include a practical

component. Evidence suggests that broader education to tackle negative societal attitudes to older people and to mental health service users may be needed too.³⁹³

Commissioners play a crucial role in shaping local services, so education and training that provides a better understanding of older people's mental health issues is essential.

7.4 Capacity building and support

Staff education and training are important but they are not sufficient to change practice without sound management structures in place within service provider organisations.³⁹⁴ Staff need support from managers who prioritise education and training and can create an environment where learning is valued. Staff also need opportunities to put their learning into practice.

To build the **capacity for change within organisations**, challenging issues must be addressed such as poor management and lack of leadership, staff shortages, high turnover of staff, high use of bank and agency staff, poor standards of clinical care, a poor physical environment and low morale. A particular challenge for service providers working in older people's mental health is how to work across interfaces with other services. An initial step would be for organisations to develop older people's mental health strategies.

A focus should be maintained on organisations in all sectors. The majority of frontline staff working with older people with mental health problems are employed by the public sector although an increasing proportion of services are commissioned to third sector organisations. Private sector organisations provide a significant proportion of mental health services so it is important that support is provided to third and private sector organisations to help them train their staff and follow good practice.

Inspection and regulation is one way of driving service improvements across an organisation. Standards must be developed that encourage organisations to take a holistic approach to recognising and responding to mental health problems in older people, particularly in care settings where the majority of older people are affected.

Benchmarking data is needed. There are significant limitations and gaps in the existing data which make it difficult, if not impossible, to measure and monitor improvements in older people's mental health services. One review of older people's mental health services in Northern Ireland stated that:

"An obstacle in undertaking this review has been the inability to comprehensively determine expenditure on existing service provision, associated activity levels and also the staff resources involved. Consequently the ability to take effective strategic decisions on service delivery is compromised." 395

Data on service provision, staff levels and expenditure are typically categorised as either for older people or for people ('adults') with mental health problems; categories must be revised to make it possible to determine what services are being provided to older people with mental health problems, by whom and at what cost. Population surveys of

mental health often include upper age limits, and restrict themselves to people living in private households; these limits must be removed so that the true scale of mental health problems in later life can be revealed. Data on unpaid carers must indicate how many are caring for older people with primarily mental health problems. Standardised data on the prevalence of different mental health problems in later life in different settings must be developed, especially at the local level, to enable service providers to know whether they are making a difference.

Performance management of older people's mental health services has been described as 'immature',³⁹⁶ partly as a result of the lack of available data. High level performance targets and indicators are needed.³⁹⁷ Information about **good practice** in older people's mental health services must be shared more widely. The risks of not doing so are great:

"As a consequence of different recoding systems being in place or even none in place, there has not been a comprehensive picture of the needs of these client groups. In addition, there has not been an overall mapping of many instances of good practice which do exist... Older people with mental health problems have not historically been clearly identified as a service user group by commissioners. Commissioning arrangements have consequently tended to be unco-ordinated and fragmented, leading to poor outcomes for older people with mental health problems." 398

Capacity for change within wider systems must also be built.

Considerable change is needed in all of the services described in Chapter 6 to improve the lives of older people with mental health problems. Change needs to be initiated and co-ordinated across the board. Making improvements piecemeal may only increase pressure elsewhere in the system. Improving performance in primary care, for example, needs to be accompanied by improved resources in the other services to which it refers patients. Building greater capacity for social care must be accompanied by adequate recognition and support of unpaid carers as 'the UK's largest care force'. The Inquiry recommends that a ministerially-led task force be established in each UK nation to coordinate and drive the improvements needed. The task forces would provide much needed leadership on older people's mental health issues (see Section 7.6).

7.5 Investment

Increased investment is needed to improve services and support for older people with mental health problems. Inequalities in funding of mental health services for 'adults' and for older people must end (see Section 3.2). Investment in services and support for older people with mental health problems and their carers must be equalised, to ensure equality with younger adults.

This will require better recognition of the economic costs of mental health problems in later life. This will also require tackling the underlying ageism which makes such inequality possible. Older people's mental health must be prioritised in order to make increased investment both possible and effective.

7.6 Leadership

The need for political, professional and societal leadership on the issue of older people's mental health is paramount. Change will not happen without leaders at all levels who have the vision, passion and courage to challenge widespread defeatism, raise expectations and show the way forward.

Political leadership has been lacking to date. Within Government, there has been confusion and lack of clarity at the ministerial levels about who has lead responsibility for older people's mental health. Lack of leadership at the top inhibits change throughout the system. We need one minister with responsibility for mental health issues for adults of all ages. This minister should provide leadership at the highest level, where there is an urgent need for a co-ordinated approach to the development and improvement of services and support for older people with mental health problems.

Professional leadership is also needed. Senior practitioners, irrespective of profession, are best placed to stimulate actual improvements in practice, by acting as champions or advocates for older people's mental health services. Their leadership is particularly needed in care settings where many older people experience mental health problems, including acute hospitals and care homes.

Senior managers also play a key role in bringing about positive changes by providing structure, deploying resources wisely and maintaining stability in times of flux and change. Senior managers are also key to enabling collaborative working arrangements which support multidisciplinary approaches which are key in services for older people with mental health problems, whose needs span many boundaries.

Societal leadership is crucial to tackling the widespread ageism and stigma which inhibit progress on older people's mental health issues. Local authorities have a key role to play as leaders in their communities. Older people with mental health problems must be supported to develop as leaders themselves.

7.7 Making a difference

What can be done to facilitate change?

- Educate and train all people who provide and commission services for older people with mental health needs.
- Devise and implement strategies for recruiting staff that will be needed to cope with the anticipated demand for services for older people with mental health problems.
- Ensure that organisations develop older people's mental health strategies.
- Develop benchmarking data and high level performance targets and indicators for older people's mental health.
- Establish a ministerially-led task force in each UK nation to co-ordinate and drive improvements across systems.
- Increase investment in mental health services for older people.
- Identify one minister with responsibility for mental health issues for adults of all ages.
- Identify professional and societal leaders to show the way forward on older people's mental health.

Chapter 8 Conclusions

The Inquiry's vision is of a society where the needs of older people who experience mental health problems, and the needs of their carers, are understood, taken seriously, given their fair share of attention and resources, and met in a way that enables them to lead full and meaningful lives. The Inquiry believes that this is achievable, and that this achievement will benefit society as a whole.

Three million older people in the UK experience symptoms of mental health problems and this number will increase by a third over the next 15 years. Depression is silently and invisibly devastating as many as one in four older people. Only 15 per cent of them will receive any kind of treatment. Men and women aged 75 and over have among the highest suicide rates of all age groups in the UK. Yet older people's mental health services have been systematically disadvantaged, suffering from low levels of investment, low priority on multiple agendas and low individual expectations of mental health in later life.

These facts should generate a sense of urgency and of anger about the lack of attention paid to mental health problems in later life. Why is there still a resounding silence?

Age discrimination remains the fundamental problem. It has emerged as a major theme in both Inquiry reports. In the first report, older people identified age discrimination, from a wide range of sources, as a barrier to good mental health and well-being. In this report, it has been identified as a barrier to much needed improvements in the funding, planning and provision of services and support for older people with mental health problems.

Recent attempts to root out age discrimination in mental health and to promote the principles of age equality and age inclusiveness are commendable but they have not been entirely successful. **Age barriers** in access to services still exist, particularly in social care. Some NHS mental health services for older people have been amalgamated with services for 'adults' in order to make them 'inclusive'. Yet this inclusivity is premised on the assumption that all older adults have the same needs and aspirations as younger adults, and can therefore be treated the same. This assumption is wrong. This is the essence of indirect age discrimination and it is just as discriminatory as blatant age-based criteria which restrict access to much needed services.

Much of the difficulty stems from a misunderstanding of what age equality means. 'Age equal' does not mean 'the same'. In addition to the removal of age barriers in access to services, **proper resourcing of specialist services** for older people who have complex health needs is needed. Without this, considerable damage will continue to be done to age equality in the name of age inclusivity. Government must take action to clarify the meaning of age equality and to enshrine the principle in legislation as soon as possible.

Even more work is needed to challenge the **ageist attitudes** that underpin society and have made it acceptable for mental health services for 'adults' in England to benefit from $\mathfrak{L}1.5$ billion investment since 1999, while mental health services for 'older people' received none.

We also need to tackle the **stigma** attached to mental illness which colludes with ageism to make older people with mental health problems invisible in much research, policy and practice. Public education campaigns that aim to reduce stigma must reflect the changing nature of the society whose attitudes they aim to improve. That society is growing older and becoming increasingly concerned with dementia and other late life mental health problems.

Depression should be recognised as a major public health issue. It is a key challenge for local authorities as they assume increasing responsibility for promoting well-being in individuals and communities, and for the NHS as it shifts its focus towards prevention. Here there are strong links with the Inquiry's first report, which concluded that action at the local level would make the most difference to mental health and well-being in later life. **Prevention** of many mental health problems in later life is possible and must be prioritised.

To date, most attention has been paid to older people with mental health problems who receive services. **Services** are undoubtedly important, particularly housing support which enables the majority of older people with mental health problems to live in their own homes; primary care where most older people turn to for help; social care which helps to promote well-being; acute hospitals where older people make up the majority of patients; and care homes where the majority of older people have mental health problems. Commissioners, inspectors and regulators help to shape local services and thus play a crucial role.

We need to shift our attention to older people with mental health problems who are not using services. At least half of older people with mental health problems like depression or dementia are never diagnosed and few ever receive treatment. These older people are likely to be relying on **support** from family and friends, who may also be older and in need of support themselves. Many older people with mental health problems **care for themselves**, and they should be enabled to do so – but by design, not by accident or neglect.

We need a co-ordinated and sustained approach to ensure that we are working towards a shared **vision** for older people's mental health in an efficient manner. To support this, we need more research and data to fill the substantial **gaps** in the evidence base. The biggest gaps are the views and experiences of older people with mental health problems themselves. The views and experiences of older people with alcohol and drug misuse problems, and people who are growing older with severe mental health problems, are also missing. There are opportunities for researchers to make significant contributions in these areas.

Adequate financial and human **resources** will be critical to ensuring that action is taken to achieve our shared vision. Many of the improvements in services rely on continuing education, training and support of the staff who deliver these services. Chronic underinvestment in older people's mental health services has led to major inequalities which cannot, and should not, be tolerated any longer.

The need for **leadership** on older people's mental health is paramount. We need people with vision, passion and courage to lead the way.

The increase in the number of older people is inevitable and welcome, and we must ensure that the numbers of older people who suffer mental health problems are minimised. We have the opportunity and the knowledge to make changes that will help benefit our society and our economy and prevent enormous suffering in the future. We must accept the challenge and take action now.

Chapter 9 Recommendations

The conclusions presented in Chapter 8 lead the Inquiry to make 35 recommendations. Recommendations 1, 3, 5, 18 and 31 require immediate attention.

These recommendations can be successfully implemented only if they:

- Involve older people with mental health problems and their carers in a meaningful way;
- Recognise and take into account the diversity of older people's mental health needs; and
- Promote the principles of fairness, respect, equality and dignity.

These recommendations should be considered alongside the recommendations from the Inquiry's first report which are listed on page 9.

They should also be considered alongside recommendations on older people's mental health services made by other bodies, which the Inquiry endorses and supports:

- National Audit Office, Improving services and support for people with dementia, 2007
- Bamford Review of Mental Health and Learning Disability in Northern Ireland,
 Living fuller lives: Dementia and mental health issues in older age, 2007
- Alzheimer's Society, Dementia UK, 2007
- National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (NICE/SCIE), Dementia: Supporting people with dementia and their carers in health and social care, 2006
- Faculty of Old Age Psychiatry, Royal College of Psychiatrists, Raising the Standard, 2006
- Department of Health and Care Services Improvement Partnership, Everybody's Business, 2005
- Faculty of Old Age Psychiatry, Royal College of Psychiatrists, Who Cares Wins, 2005

Age Concern has agreed to audit responses to the Inquiry's recommendations and report on progress in 2009.

Each National Government should:

 Establish, by 2008, a high-level task force, led by a Government minister, to co-ordinate and drive the development and improvement of services and support to meet the mental health needs of older people and promote good mental health in later life. The Task Force should work across Government to implement the recommendations from this and other investigations into older people's mental health and well-being. It should prioritise action to meet the mental health needs of older people in institutions where there is a high prevalence of mental health problems, particularly residential and nursing care homes and acute hospitals. Older people with mental health problems and their carers should be included in the membership of the Task Force, alongside policy makers, service providers, professionals and voluntary organisations.

2. Ensure that one minister has responsibility for mental health issues for adults of all ages.

The minister should lead the Task Force proposed in Recommendation 1, and provide the political leadership needed to drive change across Government.

3. Ensure that the principle of age equality is incorporated into all mental health policies, performance indicators, strategies and initiatives across Government by 2008, and ensure that older people's specific needs are identified and addressed.

Government should lead by example and eliminate the inconsistencies that exist across departments. One measure of success would be the elimination of policies defined by chronological age. Monitoring would be needed to ensure equitable outcomes for older people.

4. Introduce a duty on public bodies to promote age equality by 2009.

This recommendation also appeared in the Inquiry's first report. A legal duty would require public bodies that commission or provide mental health services to promote age equality. If the duty included legislation outlawing age discrimination in goods and services, it would ensure that voluntary and private sector organisations, which provide a growing proportion of mental health services for older people, were also legally accountable.

Increase investment in services and support for older people with mental health problems and their carers, to ensure equality with younger adults.

The Task Force proposed in Recommendation 1 should start with a review of differential growth in spending on specialist mental health services for 'adults' and for older people over the last five years. The review should examine the impact that unequal investment has had on the development of services for older people and their carers, and make recommendations for ways to equalise investment. The estimated cost of equalising access to psychological therapies for depression in England would be around £160 million. The cost of equalising access to services for people with severe mental health problems in England would be around £800 million. 400

The review should also examine the allocation of resources across the spectrum of health, social care, housing, education and other areas that impact on mental health.

The Commission for Equality and Human Rights should:

6. Conduct an inquiry in 2008 into equality and human rights in mental health services, with a focus on age equality.

An inquiry would provide an opportunity to explore the multiple and overlapping forms of discrimination experienced by older people with mental health problems.

Departments of Health in each of the four nations should:

7. Develop a comprehensive older people's mental health strategy and establish a body to co-ordinate implementation.

The strategy should address all aspects of mental health and well-being from promotion and prevention through to end-of-life care, and include health, social care, housing and other areas. The co-ordinating body should ensure that older people's mental health and well-being is treated as a priority within the Department.

8. Require Chief Medical Officers to include older people's mental health and draw attention to late life depression as a public health issue in their annual reports.

The Chief Medical Officers should promote a public health approach to tackling late life depression. They should also develop data that compares health outcomes for older people with and without mental health problems across different settings. Progress on findings should be monitored.

9. Ensure that national and local suicide prevention strategies and initiatives identify older people as a priority group.

The high rate of suicide among older people in the UK makes their inclusion as a priority group in prevention strategies across the four nations a necessity.

10. Ensure that anti-stigma and public mental health education campaigns include older people and address late life mental health problems.

A variation of this recommendation appeared in the Inquiry's first report. Existing anti-stigma campaigns, such as **see me** in Scotland, and public education campaigns like Mental Health First Aid, which aim to increase public understanding and awareness of the symptoms of mental distress, must include older people in their activities.

11. Support research into overlooked areas of older people's mental health, including the views and experiences of older people and their carers, older people with alcohol and drug problems and people growing older with severe and enduring mental health problems.

The Mental Health Research Network UK could facilitate the allocation of funding.

The NHS should:

12. Develop the Quality and Outcomes Framework (QOF) of the GP contract to create incentives for GP practices to identify and treat depression and anxiety in accordance with clinical guidelines in order to tackle the problem of under-diagnosis and under-treatment of late life depression.

Clinical guidelines state that the full range of psychological interventions should be made available to people of all ages with depression. The QOF has proved to be effective in improving the quality of care that GPs provide for all other common conditions in primary care, such as diabetes and heart disease. It is hoped that implementation of this recommendation will do the same for depression and anxiety.

The NHS and local government should work together to:

13. Ensure that strategies to promote well-being and their relevant performance indicators include and provide for older people with mental health problems.

A variation of this recommendation appeared in the Inquiry's first report. As local authorities assume responsibility for promoting well-being and the NHS shifts towards prevention, mental health and well-being must not left out, and older people must not be left behind.

14. Support the development of community-based initiatives to reduce isolation and enhance social support for older people who have, or who are at risk of developing, mental health problems.

These initiatives should be incorporated into wider social inclusion and community development programmes. They would ideally be led by older people themselves.

15. Ensure that initiatives that aim to maximise choice and control are offered to and developed for older people with mental health problems, and their carers, with appropriate support where needed.

Examples include 'self-directed support' schemes such as direct payments in the UK and individual budgets in England. These initiatives must be extended to older people with mental health problems, with support to enable this. These initiatives must also be extended to unpaid carers.

16. Involve older people with mental health problems and their carers in the planning, delivery and monitoring of services, with appropriate support where needed.

The development of new mechanisms for involvement led by older people with mental health problems would be one measure of success.

Departments with responsibility for housing, and housing authorities should:

17. Develop and review national, regional and local housing strategies to ensure that older people's mental health needs are assessed and responded to within general and specialist provision.

Relevant strategies include the forthcoming National Strategy for Housing in an Ageing Society in England. A range of housing options must be developed to meet older people's diverse mental health needs. A framework for monitoring should be developed.

Health, social care and housing commissioners should work together to:

18. Develop a comprehensive commissioning framework for mental health services for all adults which ensures that mental health services that specialise in working with older people are adequately resourced.

The framework must ensure that specialist mental health services that work with older people are properly resourced. This will ensure that older people with mental health problems do not experience indirect discrimination. The framework should include standards for referral from 'adult' mental health services to 'old age' specialists.

19. Develop standards that require staff in different settings to work with mental health specialists to recognise, monitor and respond to the known risk factors for depression, anxiety, suicide, delirium and alcohol and drug problems in older people, and monitor compliance.

The standards should include a requirement on providers to train staff in all settings to recognise and monitor risk factors, and respond at an early stage.

20. Develop standards that require services to provide regular surveillance that will prevent physical health problems from developing or deteriorating (potentially affecting or being misdiagnosed as mental health problems) and monitor compliance.

Examples of such care include regular blood pressure checks to prevent the risk of developing vascular dementia. Regular vision and hearing tests can identify sensory loss as the cause of communication difficulties which might otherwise be interpreted as cognitive impairment.

21. Ensure the provision of flexible home care that offers emotional as well as practical support to older people with mental health problems and their carers at an early stage.

To enable this, local authorities must revise their eligibility criteria for social care services to allow older people to access low-level practical support at an early stage.

22. Support the development of information, advocacy, self-help and peer support groups for older people with mental health problems and their carers.

An increase in the number of self-help and peer support groups would be a measure of success.

Voluntary organisations should:

23. Ensure that suitable mental health services are available and accessible to older people with mental health problems.

As voluntary organisations are encouraged to play an increasing role in the provision of public services, they must ensure that their services are not age discriminatory in any way.

24. Work with professional bodies, with the media and with older people to publicise positive stories of hope and recovery from mental health problems in later life.

This builds on a similar recommendation in the Inquiry's first report. Older people with mental health problems say they would like more positive stories of hope and recovery to counterbalance the pervasive sense of pessimism, defeatism and hopelessness about mental health in later life issues. One measure of success would be more positive public attitudes towards older people with mental health problems.

25. Prepare younger adults with mental health problems for transitions in later life.

More attention to the needs of people growing older with severe and enduring mental health problems is needed.

Acute trusts should:

26. Train staff to recognise and respond to older people's mental health needs, and encourage staff to contribute their skills and knowledge to improving the quality of care provided.

Training should focus on delirium, dementia and depression and target staff in all departments, including A&E and discharge planning. The development of liaison mental health teams for older people which provide support and training is one way to encourage staff to contribute their skills and knowledge.

27. Establish systems and procedures to address older people's mental health needs at all stages of a stay in hospital, from admission through to discharge.

A hospital-wide approach would ensure that systemic barriers are recognised and tackled.

Residential and nursing care homes should:

28. Establish systems and procedures to ensure that members of staff have the appropriate skills and resources to recognise, monitor and respond to depression in older residents.

Resources may include skills, knowledge and confidence; cross-cultural understanding; time for one-to-one work with individual residents; and access to mentoring support from mental health specialists.

Inspection and regulatory bodies should:

29. Ensure that the principle of age equality is incorporated and upheld in all of their policies, assessments and improvement activities and prioritise the assessment of mental health services for older people.

Inspection and regulatory bodies must ensure that they have rooted out age discrimination in their own policies first before working to ensure that services are commissioned and provided in an age equal way. Assessments should not focus only on 'adults of working age' without justification.

30. Develop standards to encourage care providers to develop systems and procedures that facilitate the identification and management of mental health problems that are common in care settings.

Inspection and regulatory bodies should start by developing standards for residential and nursing care homes because the prevalence of mental health problems in these settings is so high.

Professional regulatory authorities should:

31. Require the curricula for all basic training programmes to include modules on the assessment and care of older people with mental health needs.

Relevant authorities include the General Medical Council, the Nursing and Midwifery Council, the General Social Care Council, the Health Professions Council, the General Optical Council and the Royal Pharmaceutical Society. Basic training should reinforce the message that older people are the main users of health and social care services. Older people with mental health problems should be involved in curriculum development, training delivery and role playing.

Higher education institutions and training bodies responsible for the education and training of health, social care and housing workers should:

32. Include the assessment and management of older people's mental health needs in all basic training courses, to ensure the attainment of the necessary skills, knowledge and attitudes to address older people's multiple health problems with care and respect.

Relevant institutions and bodies include medical schools, schools of nursing and training schools for allied health professionals and for social workers. The content of the training should include the prevention, recognition and management of abuse; the importance of user involvement and community participation; and ways to support unpaid carers and wider social networks for older people with mental health problems. Older people with mental health problems should be involved in curriculum development, training delivery and role playing.

Professional bodies should:

33. Develop initiatives to improve the quality of their members' practice in identifying and responding to older people's mental health needs.

Relevant bodies include the medical Royal Colleges and Faculties, the British Association of Social Work, the professional bodies for allied health professionals and the Royal Pharmaceutical Society. Initiatives could include continuing professional development on the prevention of mental health problems in later life.

34. Work with members and with other professional bodies to define the specialist skills and knowledge involved in working with older people with mental health problems, and educate colleagues who work with younger adults to ensure that older people are not indirectly discriminated against in the services they receive.

The skills and contributions of mental health professionals who specialise in working with older people must be recognised (see Recommendation 18). To enable this, a much clearer definition of their specialty is required. Collaboration across professional boundaries will have greater impact.

35. Establish programmes to develop and strengthen leadership in working with older people, including older people with mental health problems.

Leadership on older people's mental health issues must be developed from within the professions. Relevant professional bodies are listed in Recommendation 33, and should also include the NHS Confederation, the Local Government Association, the Association of Directors of Adult Social Services and representative bodies of care home providers. One measure of this recommendation's success would be the establishment and growth of special interest groups in older people and mental health.

Notes

- 1 UK Inquiry into Mental Health and Well-Being in Later Life (2006).
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Improving services and support for older people with mental health problems

UK Inquiry into Mental Health and Well-Being in Later Life www.mhilli.org

The UK Inquiry into Mental Health and Well-Being in Later Life was launched in 2003 with the aims of:

- Raising awareness of mental health and well-being in later life,
- Involving and empowering older people,
- Creating better understanding,
- Influencing policy and planning,
- Improving services, and
- Stimulating ongoing work by others.

The Inquiry has been led by an independent board and supported by a wider advisory group and by Government participants from across the UK.

The Inquiry has worked in two stages. The first stage focused on what helps to promote good mental health and well-being in later life. A first report of findings and recommendations was published in June 2006.

The second stage focused on improving services and support for older people with mental health problems and their carers. The findings and recommendations are presented in this report.

The second stage of the Inquiry's work was supported by Age Concern. This report represents the work of the Inquiry Board and does not necessarily represent the views of Age Concern.



www.ageconcern.org.uk

Age Concern is the UK's largest organisation working for and with older people to enable them to make more of life. Age Concern is a federation of over 400 independent charities which believe that ageing is a normal part of life, and that later life should be fulfilling, enjoyable and productive.

Registered charity no. 261794.