

MOVING OUT OF THE SHADOWS

A report on mental health and wellbeing in later life

Moving Out Of The Shadows (MOOTS)

Keeping mental health for older people at the forefront of all our minds

MOOTS is the umbrella term for joint work on promoting and influencing better mental health for older people. MOOTS is co-chaired by the Older People's Programme and Better Government for Older People, and encompasses a number of national partners, see Appendix 3. For more information please contact one of the partners below.



The Older People's Programme (OPP) works with local, regional and national partners across the UK to improve services for older people, influence policy and practice, share learning and information about good practice, and support the continuous development of health, social care and housing services.

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Better Government for Older People (BGOP) is a movement of organisations working in partnership across the UK to change attitudes and services in order to achieve an improved society for older people. Our members include our Older People's Advisory Group (OPAG), national and local Government departments and agencies, older people's forums and Age Sector organisations.

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Our vision is of a world in which older people are valued for their contribution. Help the Aged is working hard for a world in which older people are valued for their contribution to society, involved in their local communities and fulfilled in their needs, hopes and aspirations.

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Chapter 1: Introduction and setting the scene

1.1 Overview of this report

On 1st May 2003 a significant national event was held to explore ways of achieving greater inclusion and quality of life for older people with mental health problems. It was organised by the Older People's Programme at King's College London (now based at Help and Care), the Better Government for Older People partnership and its UK Older People's Advisory Group, and Help the Aged. It was called *Moving Out Of The Shadows* (or MOOTS).

This event marked the beginning of a partnership between these organisations, whose purpose is to improve our understanding about mental health and wellbeing in later life, and about the kinds of services and support that older people need and want, in order to live full and rewarding lives. We began with a small, important and often missing step: listening to the voices and experiences of older people with mental health problems.

This report is the product of all the participants of that event. It is the first of a range of briefings and activities that the MOOTS partnership is currently developing. Our aim is not to duplicate what a number of other organisations are striving to achieve. Instead our work together is focused on harnessing the voices of a number of different groups and individuals - specifically older people who experience a range of mental health problems - to inform and influence future policy, practice and experiences.

The simplest way of describing our vision is: social inclusion for older people with mental health difficulties, mental illness and dementias. We want to move away from professional and organisational constructs of mental health and mental ill-health in later life - and indeed at all ages. We want to broaden this discussion out into all walks of life, well beyond health and social care, and focus on citizen-centred approaches that are shaped by what people say they want and need.

There is a wealth of information and a number of recommendations in this report aimed at many audiences. Chapter 1 provides the background to this work; Chapter 2 describes the methods; Chapter 3 summarises the experiences of participants – both positive and negative; Chapter 4 outlines the areas for action; and Chapter 5 describes the role of MOOTS in taking this work forward. The policy background is reviewed within Appendix 1.

For too long mental health in later life has been ignored. We therefore urge readers to take the time to consider the detailed content of this report, as well as using it as a reference and resource. We hope you find it enlightening and thought provoking. At times the messages may make uncomfortable reading, for which we make no apology.

The MOOTS participants and others with whom we all work are clear that services for and experiences of older people with mental health problems need to change radically and exponentially. Such change is never easy and all too often can become dominated by changes in infrastructures, rather than focussing on people's lives and opportunities. MOOTS wants to ensure that this does not happen.

1.2 Background to 'Moving Out Of The Shadows' (MOOTS)

The MOOTS partnership came about as a result of shared concerns about the lack of a coherent vision and awareness of what constitutes *good* mental health in later life; and the lack of understanding about older people's experiences of the way their mental health is promoted, protected and enhanced.

These concerns span the broader determinants of health and wellbeing that influence quality of life, as well as the current status of mental health services provision for older people. They include the challenges involved in developing and delivering responsive and effective mental health systems that encompass the whole range of supports, information, advice, interventions and service facilities that research indicates are effective and desirable in promoting good mental health.¹

Many local agencies *do* now share a common aim of developing a comprehensive 'whole system of care' that spans the range of public services that older people with mental health problems encounter and use. However, it is still the case that when this aim is translated into action (whether at a planning level or in service delivery) a number of different interpretations of what a 'whole system' constitutes become apparent. In addition, systems that are locked into supporting the most severe level of needs will find it difficult, and will need time, to shift the balance of care - in particular within the available resources.

We argue that there is a lack of understanding about what a 'whole system of care' for older people with mental health difficulties looks and feels like to older people, to staff, carers and others involved in delivering treatment and support. The current partnership of agencies involved in such developments tends to be limited to specialist NHS and Social Care services. What is required is a partnership that embraces the broad spectrum of public services, including *but not exclusively* health and social care services, non-statutory bodies (voluntary and private organisations and local enterprises), and older people themselves.

A citizen centred approach such as that endorsed by the work of BGOP and its Older People's Advisory Group (OPAG), among others, has dramatically shifted attitudes towards, and experiences of, older people as active and valued participants in shaping local and national policy and public services. A similar approach is now required in relation to mental health and wellbeing in later life.

Recent inquiries, for example into the Rowan Ward at Withington Hospital, Manchester, and Beech House at St Pancras Hospital, London, identified serious concerns about the abuse and inadequate care for older people with mental health problems. The muted public and political responses to these inquiries demonstrate the need to raise awareness and ownership and address these issues as matters of public concern.

1.3 Shared concerns and aspirations

A range of people with varied interests in mental health and older people were invited to an initial meeting jointly convened by the Older People's Programme and Better Government for Older People in August 2002. The following points capture the ideas, concerns and priorities identified by this group, which became the Steering Group for MOOTS.

¹ *Social Support, Social Cohesion and Health*, Berkman, 2000; *Potential for community programs to prevent depression in older people*, Bird & Parslow, 2002; Bowers, H - *Developing Inclusive Mental Health Services for Older People*, Mental Health Review, 2001, Volume 6 Issue 2.

What does MOOTS want to address and why?

The principles:

- Rethinking what mental health and other public services for older people could and would look like, feel like, work like if based around what works for older people in terms responding positively to their **hopes and aspirations**
- Applying the concepts, practices and lessons of **citizenship** to older people with mental health problems in accessing, influencing and improving public services
- Developing a **shared understanding of 'person centred care'** and what this means in practice for older people with mental health difficulties
- Influencing and insisting upon a **broader, holistic approach** for recognising and responding to the needs of older people with mental health difficulties, which is not constrained, but supported by policy and practice frameworks
- Keeping a **focus on prevention, inclusion, choice and control**
- Highlighting the need for strong and effective **leadership and leaders** who can embrace these concepts and work in partnership to achieve these aims
- Highlighting the **importance of investment** in developing these services

The practice:

- Explore ways of involving and supporting older people with mental health problems, and their carers, to have a **voice and influence** over services and care delivery - at all stages of their own treatment - and of local services in general
- Promote better mental health for older people, **wherever people live** - at home, in supported accommodation or in a care home
- Build **effective partnerships** between older people; their families and carers; practitioners, service providers, commissioners and policy makers working across statutory and non statutory services, and local communities
- Support and encourage a cohort of **lively and enthusiastic practitioners and teams** including carers, families, and those older people who need support
- Highlight the **skills and qualities** required, and the development needs of the entire workforce supporting older people with mental health problems
- Gather and develop accessible sources of information about **where things are working well now** in relation to practices, approaches and support systems e.g. direct payments, peer support, self-management, and community participation
- Examine specific challenges and opportunities in developing a **whole system of care that is focused on individual solutions** drawing on wider resources and support systems beyond service-based solutions
- Work with others in agreeing and applying common, **meaningful indicators and outcomes** for a) good mental health and wellbeing in later life; and b) effective mental health systems and care delivery

These priorities were identified following the presentation of a briefing paper by the Older People's Programme (OPP), attached at Appendix 1, which provides an overview of the national policy context and shares the results of a thematic review that OPP undertook to identify best practice from development work carried out in England, Wales and Scotland.

Whilst the review had identified some examples of good practice in the delivery of mental health services for older people, it primarily identified a number of concerns with current provision. Key amongst these concerns was the low level of investment in developing these services and in understanding the needs of older people with a range of mental health difficulties.

One of the purposes of the OPP review had been to map out the characteristics of an effective mental health system for older people. This proved hard to achieve due to the lack of information and agreement about what constitutes 'good practice' in understanding the range of mental health difficulties that older people experience, and the range of service options for responding to these needs. We lack a robust evidence base about what a comprehensive mental health system looks like, and what it feels like to older people and carers.

The most critical issue identified was the lack of a voice or understanding of what older people themselves value and aspire to, and what kinds of support and services really help in promoting older people's mental *health* and wellbeing.

The predominant sources of information were either about specialist mental health services (predominantly inpatient services and community mental health teams), or feedback about how difficult it is to *access* these specialist services. The information also reflected statutory agencies' preoccupations with measures of efficiency (e.g. lengths of stay and delayed transfers of care) and the lack of specialist nursing home places available for people with complex and challenging behaviours.

Our challenge then became how to move from this fairly pessimistic and '*hopeless*' position, to a more positive and dynamic future? It was at this point that the initial meeting of the MOOTS Steering Group was convened, where it was agreed that our collective focus should be on identifying and translating the experiences and voices of older people - with and without mental health difficulties - into a holistic and wide-ranging system of support across all public services. From this underpinning ethos - *that future developments should stem from the views, experiences and aspirations of older people* - further work could then be undertaken to develop responsive and comprehensive mental health services.

1.4 Linking with Age Concern England and the Mental Health Foundation

Over the last 18 months that the MOOTS Steering Group has been meeting, Age Concern England and the Mental Health Foundation have initiated a major inquiry into older people's mental health in the UK, which aims to:

- Influence national and local policy, planning and practice to achieve improved mental health for older people
- Improve the quality, capability and capacity of services in detecting, diagnosing, treating and caring for older people with mental health problems and their families
- Raise the profile of mental health issues for older people
- Provide an authoritative basis for future UK policy; research; service development

The MOOTS Steering Group has discussed possible areas of collaboration with this Inquiry to ensure that MOOTS contributes to, rather than duplicates, this work. The findings of our work will therefore feed into the Inquiry in the form of a written report, including recommendations about priority issues that need to be addressed.

Chapter 2: The first MOOTS event

2.1 Participants and objectives

MOOTS has become the umbrella term for this joint work on promoting and influencing better mental health for older people. It was agreed that we would 'launch' this work through a one day event, which was held on 1st May 2003 in Leeds Town Hall.

Our focus at this event was to hear and learn from older people's experiences of mental health problems and services; from those who work with, care for and support them; practitioners; researchers and policy makers; managers of public services; and other older citizens, including those who participate in local, regional and national decision making bodies (e.g. advisory groups and implementation teams). All of these stakeholders have important contributions to make about how services could be improved and what helps to maintain *good* mental health and enhance wellbeing in later life.

Approximately 65 people attended this event, from a total of 150 people who were sent personal letters of invitation. We wanted a fairly small group of participants, and opted for a process of selection to ensure that this first event engaged a mixed group, many of whom were older people, who we knew would genuinely want to explore a broad range of issues and would understand the approach we had adopted. This was important in building a partnership with one another to not only explore mental health and mental health services openly, but also to demonstrate to others how to achieve greater inclusion *with* older people with mental health problems.

We were clear that what is required is a new direction for how people regard mental ill-health in later life - and the kinds of support that will promote better mental *health*. We know that there are different opinions about this, and that MOOTS will need to address these opinions if the new approach we seek is to be achieved.

Our objectives for the MOOTS event were:

- To initiate and develop a dialogue with a wider group of people interested and involved in providing, developing, researching and using mental health services
- To articulate more clearly the experiences and aspirations of older people with mental health difficulties
- To share experiences and information about what is happening around England, Wales and Scotland regarding mental health in later life
- To explore ways for local agencies to develop and deliver innovative mental health services and support for older people with a range of mental health problems
- To gain a better understanding of the support needed by local services and communities to develop a whole system of care based on a person-centred model
- To produce a report which brings together all the issues, voices and ideas including a possible way forward for older people, carers, communities, policy makers, researchers and local services - both providers and commissioners, and statutory and non statutory sectors

2.2 Programme and methods: a thoughtful and collaborative model

An interactive event programme was devised by the MOOTS Steering Group, including presentations from people with different perspectives, and from different places across Britain. Our goal was that everyone should have the opportunity to contribute and share their experiences, ideas and opinions.

Two sessions involved all event participants identifying the key factors for determining good mental health and wellbeing in later life, and the range of supports that enable this to be experienced. The first session used a story telling technique in small groups, of approximately 7-8 people, to explore three key questions.

1. What are good/positive experiences, and what enables these to occur?
2. What are bad/negative experiences, and what makes them happen?
3. What are your hopes, aspirations and ideas for future support and help to improve health and ensure wellbeing for older people with mental health problems?

The session asked the groups to reflect on their own experiences of mental health problems, and of mental health and other services in supporting them. Participants were encouraged to share stories that were drawn from others' experiences if this was easier, e.g. a friend, a relative, someone they care for.

Each group recorded their responses on bright sticky-notes which they posted on flipcharts around the room in colour coded areas. This use of visual displays was important for capturing the emotional elements of the subjects under discussion. The method created a simple and accessible way of recording contributions, including non-verbal contributions in the use of pictures or symbols.

The second session was a more open discussion forum, again in small groups, focusing on an additional set of four key questions.

1. What matters most for helping you and people you know feel supported; and that your/their mental health and wellbeing is being sustained and improved?
2. What needs to be in place locally to support people?
3. What needs to happen to help more people take part in days like this and other opportunities, to have a voice (locally, regionally or nationally)?
4. What should we – MOOTS - do next to take these messages forward?

As our main vehicle for achieving the inclusion of all participants was through the focused discussions in small groups, the role of group facilitators was critical to the event's success. Each group had a nominated facilitator, who had been briefed about their role before the event, and whose role included the following tasks:

The critical role of the group facilitator

- To welcome participants, put them at their ease and assist with introductions
- To explain, whenever necessary, what was involved, what we were there for, and that people's experiences were valued and needed
- To ensure everyone was comfortable with the idea of sharing experiences and stories, and to determine if anyone needed additional support (e.g. if they would prefer to talk to someone on a one-to-one basis)

- To help people tell their stories, and to listen to others' stories, so that all voices were heard
- To ensure dialogue and conversations were mutually supporting and safe
- To follow the structure of the sessions to ensure that we covered all the issues, whilst hearing what people had to say that may have differed from our programme
- To capture and record the key issues arising out of conversations around the table
- To help people to record for themselves their thoughts (in words or pictures)
- To keep to time

The facilitators who undertook this role are included in Appendix 2.

These exercises, the presentations from invited speakers and the plenary discussions generated a wealth of material and ideas. The experiences of participants are described in Chapter 3, the priority areas and ideas for action in Chapter 4, from which a programme for MOOTS to take forward is outlined in Chapter 5.

2.3 The start of a new journey: personal and professional reflections

“When it comes, it degrades one’s self and ultimately eclipses the capacity to give and receive affection. It is the aloneness within us made manifest, and it destroys not only connection to others but also the ability to be peacefully alone with oneself”

from ‘The Noonday Demon’ by Andrew Soloman, 2002 p15

This quote is taken from the opening presentation from Mervyn Eastman, Director of Better Government for Older People (BGOP), who had offered to share his personal and professional experiences in relation to different ‘states’ of wellbeing and of mental health services and supports.

This spirit of sharing experiences was central to the MOOTS event. We wanted to learn from listening to and reaching a better understanding of what helps when people’s wellbeing and sense of self is adversely affected - for whatever reason and at whatever age or stage of life.

Mervyn’s reflections set the tone for the day and connected very strongly with people in the room. We were asked to include the text of Mervyn’s speech within our write up by a number of people who attended the event. This follows below.

“ Our focus today is on hearing the voices and experience of older people and when the organisers considered how best to set the scene with the opening contribution, I agreed to offer my own personal and professional reflections. Thus, whilst used to giving keynote speeches, here today with you, I for the first time publicly and with a degree of nervousness, offer a backdrop against which we can debate, explore and hopefully ‘start a new journey’.

What is this journey? How is it new and what is wrong with the existing direction of travel? Indeed what will be different if we change, in partnership, our direction? What do we mean by ‘Shadows’? –mental ill health; the services we have constructed to meet older people’s mental health needs; the professionals, academics, clinicians and policy makers who define, deliver or evaluate those services? What is required to move out from beneath these shadows?

We begin with a range of assumptions. That the existing direction of travel is flawed; the services constructed continue to be ineffective for both those who design and provide mental health provision and those who access them, or who cannot access them. All are victims of a health and social care construct that excludes older people from their basic human rights, and professionals from realising their own aspirations. Not to begin this day by accepting these assumptions means that we have invited the wrong people.

Today is not about debating these assumptions (that would be an entirely different event) - but to explore how we move out of these shadows. The links we have present in this room and the potential influence from those links can fundamentally change the direction of travel and create in the longer-term greater social inclusion and quality of life for older people with mental health problems.

What therefore are my credentials to reflect? Firstly, as a social care professional for over 30 years in the field of older people; and secondly having commenced my own personal journey into depression in 1999, and remaining on that road to ‘full recovery’. Being beyond ‘unhappy’ in a world of utter hopelessness between November 2000 and February 2001, that total degradation of self and dislocation of connectivity with others. Life was not worth living. I was meaningless to myself.

Today offers, through the kind hospitality of Leeds City Council, an opportunity if we wish to grasp it of heralding a change of direction, building upon what works by demonstrating:

- Older people’s engagement is central to re-framing exclusion into inclusion
- How to re-shape our understanding of mental health in later life
- That older people, providers and commissioners are in fact on the same journey and share responsibility, and indeed can share the same aspirations

We hope that today’s deliberations will influence policy across the nations, reshape practice and rebalance the conceptual frameworks that currently dominate health and social care services.

A personal journey into and out of the shadows

I was initially going to write some quotes from a notebook I kept during that period of hopelessness. But for dramatic effect I have brought the notebook with me and will quote directly from its pages:

‘There is a strange and unwelcome demon that seeks to devour me. The demon is recognisable though I am unclear of its shape or size. A demon that was conceived and nurtured in the deepest recesses of my ‘self’. A depression bordering on distress that wants to take me apart piece by piece. All that made me what I am; my sense of worth; my sense of esteem, that makes me – me, undermined. One hour I see it. It disappears, only to return. The demon of failure. So what I knew was always there has now a shape, though its size is unknown.

- o -

Suicide notes are, I discover, not easy to write! There are no pro-formas available in the Teach Yourself Letter Writing literature. To whom, or what do you address the note? What kind of paper should you use? How do you sign it ‘yours’, ‘regards’, ‘with fondest best wishes’, ‘piss off – I’m off’? A dilemma. I am not professionally unfamiliar with suicide but with being a ‘potential suicide’; the ease in which I thought notes were written certainly was a misjudgement! But perhaps most suicides are misjudgements - and true failures are those who actually succeed by dying... There is a kind of ridiculousness about the whole process, from planning the how and when to the most difficult part of explaining why. But who needs a why? Not at least by way of note...

- o -

Paroxetine 30 mg would I believe have been useful for Mary Queen of Scotland. Her depression, (and she had a lot to be depressed about), lost her much. She was indeed a ‘fatal queen’ and her charm no shield against the court intrigues of Edinburgh and Richmond...

Energy is gradually returning and with it increased focus and perhaps a self-confidence that is repairing itself. My depression could be worse, my demon more angry. Yet I remain fragile and need my refuge. There is nevertheless a sense of increased optimism and a desire to move out of my existing victim status... Doom does not overwhelm me, but remains my backdrop every hour of the day.

- o -

Looking back now at the highs and lows of the journey, I reflected on what key elements were in place which contribute to my current feeling of 'well-being'. Standing on the eastbound central line platform of Tottenham Court Road Station, glancing around to see if there were children who could witness my killing the demon, is I hope in the past. But from Tottenham Court Road to Leeds Town Hall was not a single step. For me, personally, those elements leading me to this podium were:

- A close family network, especially the children
- A general practitioner whose practice was based upon my inclusion in all decision making about treatment
- Medication
- Reading (everything)
- Writing in my red notebook!
- Starting a project (researching the history of older prisoners)
- A holiday (in April 2001)
- A new job (Summer 2001)

Translating the personal to the more general, it could be argued that there were five key components, five rays that eventually removed the shadows, that offer a framework for our discussions today:

1. A network of people that reinforces 'belonging'
2. Inclusion and participation in the diagnosis, and treatment strategies
3. Access to services on a virtual 'demand basis' and on the individual's terms
4. Resources to exploit leisure, learning opportunities and personal activities
5. A belief in 'employability' – the chance to have a 'meaningful future'

Professional reflections

Lorna Easterbrook, in an excellent publication² suggests that there are three policy frameworks relating specifically to how mental health services and structures impact on older people:

- The National Service Framework (older people);
- Integration of the Care Programme Approach (CPA) with care management
- The draft Mental Health Bill

She also recognises the wider policy landscape that affects the mental health of older people - the wider determinants of 'health'.

We believe that the important policy issue and challenge, is to view mental health and ill health in the context of the individual and the community. Judy Worr questioned in her contribution to a December 2002 Seminar 'A Joint Inquiry into Older People's Mental Health'³ ...whether any service will really understand – the essential me?"

² Moving On From Community Care: the treatment, care and support of older people in England, Age Concern England, 2003

³ Held by Age Concern and the Mental Health Foundation

Thus, whether we are exploring the promotion of health, risk, or the services available, the key is the citizenship of the older person and not the labels of ageing, mental ill health, or patient. My own journey demonstrated that I was an individual, with resources available to exploit as part of my treatment strategy.

The experience of other people can be different - as has been well documented. From the work of Sarah Wellard (2003) we know that 50 per cent of women using mental health services have experienced violence and abuse. They are, like all of us, growing older. Women more than men are likely to suffer from anxiety or phobias and be misdiagnosed. One in ten women is suffering from a depressive disorder, and yet the needs of older women with depression or dementia are given a low priority.

Other professional contributions

Last year, the Department of Health's report on Women's Mental Health, though welcome, came without targets, timeframes or links to the National Service Framework for Older People's Standard 7 on 'Mental Health and Older People'.

From Peter Beresford, a long term user of mental health services, comes a compelling argument that participation of service users is defined by professionals on a divide and rule tactic. From Melissa Ben, that one in four adults will, during their life, suffer a mental health problem; she also emphasised the gender-blindness within mental health services. From Katie Leason, at a conference celebrating the success of the National Service Framework for Older People, that whilst there is much to celebrate, there has been neglect of Standard 7. She highlighted the double stigma of older people's mental health, at the end of the priority 'pecking order' and, despite Department of Health guidance, the ongoing confusion between the Single Assessment Process and Care Programme Approach.

From Hilary Arksey and Steve Gallard, exploring the experience of research processes, that research discounts the experience and expertise of mental health users; is too narrow in focus; engagement and participation mechanisms lack imagination; users constantly challenge how mental ill health is defined; the lack of choices available; and the institutional racism (my interpretation) of black and minority ethnic communities excluded from mainstream health services.

Finally, the obsession that many gerontologists have with depression and dementia when exploring older people's mental health is highlighted by Betty Friedman (The Fountain of Age, 2000).

...so to move out of the shadows

We started with the assumption that we need to change direction. We also start with the belief that we need to:

- Use best practice as the signposts
- Explore a wider and joined-up policy agenda that challenges the current conceptual frameworks used to understand and 'treat' mental ill health
- Regard older people as experts and forge a partnership between older people and professionals
- Challenge and rebalance the power within mental health services

Mental ill health is a cruel reality and an oppressive shadow, and we - together – need to get behind the symptoms and disease models and reclaim 'the essential me'. That reclamation could define the new direction of travel. By positioning older people at the centre of policy decision making and diagnoses, treatment interventions and mental health will be redefined. By building on and celebrating best practice that reflects the citizenship of the individual and their inclusion in the communities in which we all live, we will - I hope - make a reality of 'our beautiful minds'."

Chapter 3: Learning from experiences: cross cutting themes underpinning mental health and wellbeing in later life

The five themes that are presented in this chapter are those that the MOOTS participants most frequently or strongly identified as making a *positive* or *negative* difference to mental health and wellbeing in later life. They include key factors that influence older people's experiences of services when mental health is impaired.⁴

The low profile of statutory services and the role of professionals is noticeable. This of course may be influenced by the nature of the audience at the MOOTS event, who were well enough to attend an intensive conference such as this. However, this also reflects key findings from research into mental health and wellbeing, into ageing, and with people who rely on support from these services (Baker, 2003; WHO, 2002; Herman, 2001; Secker, 1998; Harding, 1997; Oliver, 1993). What makes a difference to our sense of wellbeing goes far beyond the current remit of health and social services, important though they are for many people's day to day survival.

3.1 Visionary leadership at all levels

The importance of clear, enabling leadership was a recurring theme. Participants were concerned with the need for a much stronger direction for developing mainstream and specialist services for older people with mental health problems. They were able to identify examples of positive styles and ways of improving services and support at both individual and community levels, that epitomised for them 'good leadership'. They were also able to pinpoint instances where this kind of direction was lacking.

Visionary leadership also means being infectiously enthusiastic about what is desirable, and required, to ensure things work well for individuals. At the heart of this style is the value that leaders place on older people's *experiences*, to challenge the still dominant view of older people with mental health difficulties as dependent and passive. It was pointed out that such leadership needs to exist not only at senior levels of services and systems, but at every level and across *all* service elements.

The feedback suggests that there is currently a lack of a clear direction and leadership not only within and across health and social care services, but also in other areas of public policy and service provision. These include important, contributory aspects such as housing and supported accommodation, employment and benefits, transport and leisure, advocacy and befriending services, and health promotion services.

Nowhere was this more apparent than in the need for greater coherence in commissioning activities and arrangements. By this we mean the cycle of activities involved in mapping needs, planning responses, designing services and commissioning providers to deliver them, and ensuring that they meet the needs identified⁵. Service commissioning needs to be coordinated strategically across services to ensure a shared approach, direction and resources. This message reinforces the findings of the Older People's Programme, Appendix 1, which identified concerns and offered suggestions for improving strategic commissioning arrangements for the whole range of public services that support good mental health.

⁴ These features are similar to those identified by these same organisations in *Living Well in Later Life* (Bowers et al, IAHSR, 2002).

⁵ See *Older People – building a strategic approach*, Audit Commission, 2004; *All Our Tomorrows*, Association of Directors of Social Services/Local Government Association, 2003; *Integrated Services for Older People – Building A Whole System Approach in England*, Audit Commission, 2002.

Visionary leadership is also required to tackle the fatalism and ignorance about ageing and mental health, which is at the heart of the negative experiences that people shared. Much has been written about the need to combat ageism, not least as a result of Standard 1 of the National Service Framework for Older People - 'Rooting Out Age Discrimination'. Much has also been written about the negative impact of the stigma of mental illness. What is less widely addressed (although this is gradually beginning to change) is the discrimination in how older people with mental health problems are understood, treated and represented. The box below summarises the key points made by participants in relation to this issue.

The fatalism and ignorance about ageing and mental health

- Too many of us still equate old age with illness, disability, dementia and passivity
- A common belief that mental health problems in later life are inevitable and not treatable; coupled with a prevailing attitude that all older people who have mental health difficulties require long term care (eg residential accommodation)
- The limited range of support options that are available due to a perception that older people will not benefit from diverse, creative approaches. The 'Berlin Wall' between adult mental health and older people's mental health services epitomises this inequity of opportunity and of access
- The culture of blame and fear within services, both mainstream and specialist, so that those who '*dare to challenge*' the status quo are often seen as troublemakers
- People associate mental health services for older people with poor treatment regimes and programmes of care, and this is not always the case - there are pockets of excellence in most places

The key message about leadership was the importance of having people who recognise good practice and innovation (as defined by older people as well as experts), and who understand the factors that influence positive experiences. Many people do not know what good practice is⁶ or where it exists, and there was a desire to raise the profile of what is working well, and to learn from these examples.

A related theme was the concern about how the low profile of mental health services for older people, both to those inside and outside 'the system', affects both access to these services and how people experience them. They described that working with older people with mental health problems is seen as 'not sexy'; and there is a perception that staff are 'second class citizens', a point which is also reflected in the typically high turnover of staff. Another example of this lack of positive identity is that service environments are often of poor quality, in the worst buildings, in isolated parts of hospital sites or run down areas of towns and cities. This was seen as a crucial area to be tackled by new, visionary leadership.

⁶ Also a finding of the Older People's Programme briefing paper, Appendix 1

3.2 A collective and proactive approach

This theme includes a number of conceptual and practical considerations identified about the style of service planning and care delivery. A strong message made by participants was the need for a 'collective' style, which is described below.

Collectivism for older people's mental health

- Positive experiences of older people working with other older people to elicit their views; and with staff at all levels to share and use these experiences
- Different groups of interested and involved people working together to reach individual as well as collective solutions to complex problems. This clearly requires different groups to communicate effectively with one another, which they may need to learn
- A focus on older people's views of their own needs and aspirations - via an ongoing dialogue with older people - that informs service developments and ensures that care delivery remains firmly person centred

A number of concerns were expressed connected to experiences of (mostly) health and social care services, which were typified by the *absence* of a collective approach to the identification of the values and priorities of services.

Why do we need a collective and proactive approach?

- The options for support that are available (including specialist as well as mainstream services) are not connected up, so it is easy for people to slip through the net, even after they have accessed one part of the 'system'
- Professional boundary disputes are too common: older people with mental health problems and people supporting them hear "it's not our responsibility", especially when multiple services are involved e.g. a mix of physical and mental health needs
- The absence of support when things *first* go wrong - which can lead, or add, to greater social isolation, such as the lack of help in dealing with grief and loss
- When they do access help, it is not always easy to be 'heard', so many older people and carers give up after a few attempts
- The lack of access to a wide range of support and interventions (and certainly not the same range as services for people aged under 65 years)
- Professionals, managers and policy makers, individually and collectively, need to be more transparent about options for support to service users and carers
- Staff working within and across services appear not to be approachable and accessible, not only to older people but also to their colleagues – the practitioners and managers working within these services
- A professional 'blame culture' prevails, which has led to a disabling fear of litigation, especially with regard to discussions about 'risk', and it was noted that it tends to be professionals who think of 'risk' first, not service users
- Funding priorities often set the agenda, rather than older people's views and what is profiled on the research and policy agenda on mental health in later life is often not what older people value themselves. An exception is the studies by voluntary and independent organisations, although these still tend to focus on dementia

It was stressed that this collective approach to service planning and care delivery is also more likely to result in *proactive* systems rather than *reactive* responses to requests for help or to crises. All participants expressed their dissatisfaction with the current style of mental health service provision, which they described as 'reactionary' and focused on those in greatest need:

"Things have to come to a crisis point before action can be taken"

They described the contradictory nature of services that are 'non-interventionist' when they could and should be - in the early stages of a problem occurring. There is often no recognition that someone needs support, due to the lack of early detection. Services are then 'over-interventionist' once needs have reached a crisis, or a level where they are recognised by statutory services. At this stage, responses often ignore those wider aspects of support which people identified as beneficial to their own sense of wellbeing, and instead can intrude on life, in such a way that 'the essential me' becomes lost.

3.3 Holistic and humane approaches

"See me as I am inside, how I feel, not what I appear to be"

'Holistic' approaches were identified as those occasions where options for treatment and support extend beyond medical interventions, and focus on the broader quality of life as defined by the older person. Such approaches see and understand the older person with mental health difficulties as more than the label of 'user'.

"Very sick people must be listened to. The medical profession must take into account a consideration of people's voices, religion and wishes"

The following points were offered as examples:

Holistic approaches to mental ill-health in later life

- A sense that the people supporting me know and respect 'the essential me'
- Not feeling alone or lonely, especially if you choose to or have to live on your own
- A sense of belonging and feeling valued
- Friends who stay in contact - and with whom you stay in contact too
- A listening ear - feeling that there is someone out there who cares
- Continuity and sustained support - not just a few days and not task focused at the exclusion of all else
- Having things to do, opportunities to learn and be stimulated, being able to contribute to others' learning and stimulation - a sense of purpose
- Having a package of treatment and support options that includes a variety of mechanisms, including (but not exclusively) medication
- Close monitoring of treatments (e.g. not being over or under medicated) in order to achieve a situation where I can take control of my life, so I can make important decisions that affect my quality of life – to improve my control and choice

Example: One person shared their experience of being given the use of a car to increase their mobility. This meant they were able to get out, meet friends, and attend classes - to increase the size of their world and support network. This gave them greater control and choice and profoundly improved their quality of life.

Whilst it is clear that a holistic approach extends far beyond health and social care services, a holistic approach *within* health and social care is essential, in order to extend the consideration of older people's mental health beyond *specialist* mental health interventions to encompass the wider spectrum of health and social care.

"The human face of caring and supporting someone is not valued"

Unfortunately, services, specifically specialist mental health services, tend not to address wider aspects of people's lives, such as their quality of life, or how to break cycles of deprivation and depression. Participants described their experiences of non holistic approaches and the impact of negative stereotypes both of old age and mental illness.

Non-holistic approaches to mental ill-health in later life

- Valuing practical and technical interventions over caring for someone's emotional, psychological and social needs
- The lack of facilities and stimulation for in-patients, related to a lack of understanding of older people's mental health within general and acute hospitals
- The tendency for services - and society generally - not to encourage people to think about active ageing, in terms of protecting and enhancing their mental health and wellbeing, and not to challenge stereotypes about the inevitability of frailty
- Problems with communication and what some called the '*professional arrogance*' they had experienced. Where services and interactions with others had not been '*person centred*', the responses and interventions had not been individualised, humane, nurturing - or effective

In all of the positive experiences described there is a common theme: the importance of experiencing 'the human touch' in support from others - whether formally through statutory services or informally through personal networks. This humane response was illustrated as when someone spends time with you and hears and sees you as a whole person. In other words, when there is a feeling that people are there for you:

"Someone heard Sheila, saw Sheila, listened to Sheila."

"Having a sick relative...the last year of their life was so meaningful to me ...I was there when she needed me most. The love I was given ...I shall never forget"

Equally clear was the message that quality of life must address the central importance of 'home' for engendering a sense of wellbeing. The need for all staff to understand the contribution that familiar, safe and supportive environments make to a person's mental health and wellbeing was particularly emphasised. It was felt that this is often overlooked and that decisions about accommodation and moving home are all too often rushed and confusing. Decisions about where and how you live must be factored into any decisions about care and other support arrangements. The impact of isolation and "*growing old alone*" was also raised – in part as a fear, as well as a reality for some older participants.

For many there was, importantly, a perception that many practitioners, managers and leaders in the field of mental health services for older people *are* keen to move beyond a narrow 'user-only' understanding of their clients. However, there was a strong message that it is difficult to engender and sustain the levels of enthusiasm required to shift the still dominant view of older people with mental health difficulties as dependent and passive.

There is therefore, an urgent need for all public services and older people to develop a shared understanding of what a 'holistic' approach means and how it may be achieved. It was clear that this is influenced by many factors, including your situation and level of needs; prior experiences and expectations; and how far you are able to take up public services, especially those outside of health and social care.

This theme touches upon the important issue of *equity* of opportunity in access to services and support. Currently there is a wide divergence of opportunity and this clearly has an impact upon health and well-being. Participants expressed their concern that such inequities breach the 1999 United Nations 'Principles for Older Persons', which was displayed around the walls of the MOOTS event and is summarised below.

Summary of the UN Principles for Older Persons, 1999

- 1. Independence:** access to food, water, clothing, shelter, health care; opportunity to work or gain income via other routes; to determine when and at what pace to withdraw from labour force; access to education and training; to live in safe environments; to live at home for as long as possible
- 2. Participation:** to remain integrated in society, participate actively in formulation and implementation of policies that directly affect their wellbeing; to share their knowledge and skills with younger generations
- 3. Care:** should benefit from family and community care and protection; access to health care to help them maintain or regain the optimum level of physical, mental and emotional wellbeing
- 4. Self fulfilment:** pursue opportunities for the full development of their potential; access to education, cultural, spiritual and recreational resources of society
- 5. Dignity:** able to live in dignity and security and be free of exploitation and physical or mental abuse

(The full text is available at: www.un.org/esa/socdev/iyop/iyoppop.htm#Principles)

3.4 Community based support

"In giving you receive"

All of the support mechanisms under discussion here need to be locally based and accessible, yet many older people, carers and staff, do *not* know what is available locally to support people or know how to access it. It was emphasised that community based support means community based *people* - including family and friends, neighbours, staff and volunteers, as well as professionals.

There was a strong message about people's positive experiences of being *directly* involved in providing the kinds of local support and help that others said they needed and benefited from. So community based support emphasises *mutual* support and reciprocation as well as ways of improving access to locally based services and professional help. There were good examples of services run by older people for older people, and of community support groups and support networks organised by people who had experienced mental ill-health themselves. Other examples where positive community-based support had been experienced included help from the church and other faith organisations and from friends and neighbours.

3.5 Self determination and empowering relationships

This theme highlights the personal attributes, circumstances and relationships that can help to alleviate distress, and sustain people during difficult times.

Self determination and resolve were particularly referred to as those personal qualities and skills that helped people cope with times of mental ill-health. Discussions also included the need for people to have or to develop 'coping strategies'. Some shared techniques they had developed themselves, or had adopted, in order to not only survive but also, in time, to thrive.

A key element of this theme is the importance of people acknowledging to themselves and others that they had survived, were surviving, or would survive. Equally important, and at times more so, was that those around you are supporting you in this, including professionals, family, friends and carers. This positive determination had helped people - often someone had encouraged them to carry on, to find different ways of managing the difficult times and to recognise the better times.

Related to this is the importance of positive and encouraging relationships that enable people to find and develop their own resolve and determination. This kind of empowering support was recognised as being complex in nature. Examples of both positive and negative relationships, and their impact on mental health and wellbeing, were highlighted.

Often the people closest to you can find it hardest to help you find your own way - especially when your illness can have severe and distressing consequences for them. Participants described their experiences where people had valued and actively encouraged them: "when people help you achieve your goals". Sadly this often happened outside of mainstream and specialist services. One person declared: "If I needed help it wouldn't be from someone from a public service."

The need for more accessible advice and practical tips to help families, partners and carers for older people with mental health problems to develop these kinds of approaches was identified. The need to support staff to develop these techniques was also seen as vital.

Just as people identified the positive impact of empowering and enabling relationships, so they also highlighted the devastating consequences of disempowering and *dis*-abling relationships on mental health and wellbeing. These encompass personal and social relationships, and relationships with professionals and others who support them in a formal capacity. The following points capture these factors.

Factors which contribute to a feeling of disempowerment

- Not being attended to, listened to, respected
- Being over attended to, or being supported in such a way that the supporter takes control and dominates your life, makes decisions for you
- When someone undermines the capacity and capability of another person to choose, and to exercise personal authority and control

Also of concern are the consequences of having restricted - or for some the absence of - nurturing relationships. Examples were given of people living in care homes with restricted access to family and friends; and others who may be 'housebound' or who experience decreasing social networks.

There were a number of stories that reflected the impact of losing control and conceding power, over key decisions about one's life, to professionals and others who are not part of your personal network. The examples quoted below relate to a lack of choice over how services are provided, where people live, and even where they die.

"Individual want(ed) to die at home but GP insisted on a mental health assessment to remove her, despite there being no evidence of mental incapacity"

"92 yrs old lady, physically disabled...verbal coercing, abuse. No choice. Forced imprisonment...GP choice to place in mental health establishment. Not being heard"

This type of misuse of power was seen by many to be tantamount to abuse. It was suggested that the erosion of personal autonomy and control should be regarded as a form of elder abuse, in the way that emotional abuse is now understood as a form of abuse.

The literature on child protection includes consideration of when a programme of care is below acceptable standards, and when the system itself is inappropriate and ineffective to meet individual needs. These factors could be adapted and incorporated into existing classifications of elder abuse.⁷

⁷ e.g. See also 'Placing elder abuse within the context of citizenship' by BGOP and Action on Elder Abuse, 2004, available at www.bgop.org.uk/pages/research.html

Chapter 4: Priorities and actions for policy and practice

This section presents the ideas generated about what priorities need to be addressed to drive this agenda forward. These next, vital steps are primarily focused at a local level, although some will be best approached at a regional level, and some require a clearer policy direction and support from Government.

It covers a wide range of options and opportunities for maintaining and enhancing mental health and wellbeing, at all stages of life. Some areas highlight where further work is needed, whilst others call for harnessing what works now, to spread good practice to those areas experiencing difficulties. They serve as powerful reminders of what really matters to older people regarding their mental health and wellbeing.

These actions are the collective responsibility of many different organisations and individuals, including policy makers; those with responsibility for developing and delivering public services; and local systems of health, social care and housing services. In addition there are messages for the voluntary agencies and community groups who support older people with mental health needs, and for all local communities, about building a stronger and brighter future for people of all ages who experience mental health difficulties.

It is significant that the discussion of priorities and actions elicited the greatest amount of feedback from MOOTS participants. People are eager for a new direction and new approaches to understanding mental health and ill-health in later life.

The wealth of ideas are grouped here into three areas:

- Inclusion and quality of life
- Services and delivery
- Wider national influences

4.1 Inclusion and quality of life

Understanding quality of life and person centred care

“The right to a good quality of life”

The priority concern for all was the need to raise awareness and understanding of what quality of life means to and for older people with mental health needs. This is closely associated with the notion of ‘person centred’ care, which is now central to most policies and strategies for improving older people’s services (e.g. the National Service Framework for Older People, the NHS Plan, All Our Tomorrows).

“Mental health is integral to quality of life”

Participants spoke about there being a "hierarchy of needs" that spanned environmental, emotional, physical, spiritual, and above all the highly individualistic needs that determine and shape someone's character - those things that if lost will damage "the essential me".

“If I needed help, it... would be from someone with time to listen, to be holistic”

They suggested ways to change the culture of service provision to embrace the issue of the quality of life for individuals.

Service provision which embraces ‘quality of life’

- Valuing the individual older person and their thoughts, emotions and feelings
- Better opportunities for services users to share their ideas and contributions: listening to the people who have the problems - and often many of the solutions
- Encouraging the development of closer relationships between practitioners and service users, based on mutual respect
- Instead of asking ‘what do you want to do with your time?’ ask ‘what are your dreams, aspirations, wishes?’ to refocus on what is important to the individual, rather than what is currently available through traditional service routes
- Changing attitudes through effective lobbying for all mental health needs to be met

Figure 1 illustrates the points that many emphasised, describing the inter-dependency between, and the multi-faceted nature of, mental health and quality of life:

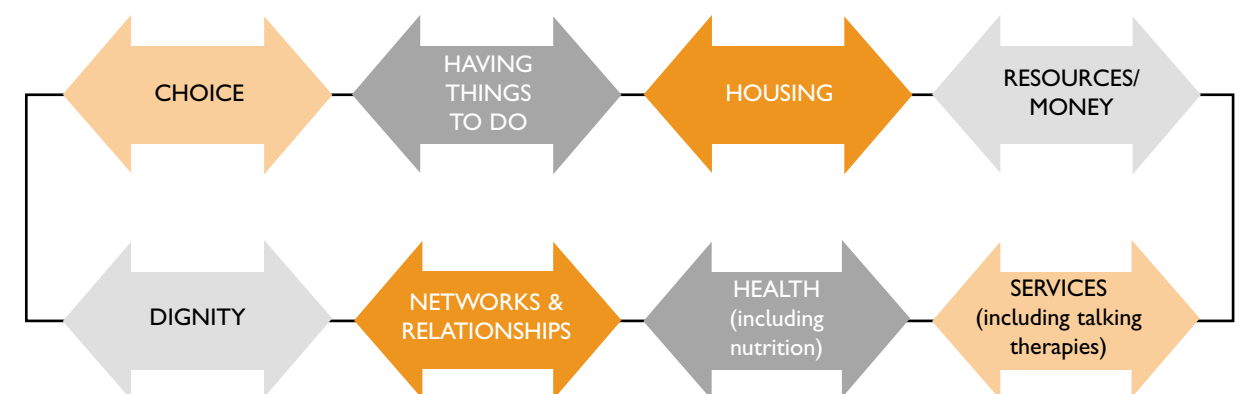


Figure 1: Promoting and protecting good mental health and wellbeing in later life

Examples of the kinds of ‘ordinary’ activities and opportunities that participants wanted to see more older people with mental health needs taking up, included sports and physical activities for both men and women. One example was support to go to a football match instead of a more mundane task such as visiting a day centre or waiting for a home visit. Clearly the practical tasks are important, such as help to do the shopping, but these tend to dominate at the expense of encouraging people to continue doing the things they find enjoyable - or trying something they’ve never done before. Importantly, people may need help to participate - or even to think of an activity themselves. Other examples are outlined below.

Developing a range of creative options that embrace health promotion

- Learning opportunities, from evening classes to opportunities for higher and further education (including book groups, writing, art and language classes)
- Community responsibility (e.g. on parish council, village or town hall committees)
- Involvement in leisure and education programme development
- Reminiscence projects
- Focusing on options to have some fun (e.g. beer and skittles), not just the very practical, necessary ‘health’ tasks

- The importance of supporting the development and continuation of positive relationships, such as volunteering and befriending schemes, between younger older people and older older people, and across wider generations, including ‘Listening Ear’
- Intergenerational opportunities e.g. helping in schools; joint computer classes between younger and older people; mentoring or buddying schemes such as those facilitated by the Beth Johnson Foundation

Promoting and protecting mental health for all older people

The focus on improving mental health and wellbeing for and with older people can easily be lost when discussions become centred on services and organisational systems – important though these are. Participants emphasised the need for a stronger focus on health promotion and protection.

What we mean by promoting mental health for older people

- More advice, information and practical assistance for planning ahead and making choices, starting with people in mid life (e.g. from 50 years) onwards
- People at *all ages* are better educated about mental health in later life, e.g. information for people whose older relatives experience mental health problems
- Raising the level of awareness and understanding about mental health and ‘active ageing’ with policy makers, commissioners, service providers and practitioners
- An appreciation that achieving and sustaining good mental health in later life requires a broad approach - recognising the importance of learning and development opportunities and housing, leisure, environment and transport issues
- A focus on preventative approaches to promote and sustain independence and good health. Stronger links are needed between strategies to improve mental health and strategies for older people as a broad population e.g. the recent study on promoting independence and wellbeing⁸ appears more focused on physical needs rather than equally on emotional wellbeing. Where mental health issues are identified they often refer to dementias, rather than a wider view of mental health
- Conducting more research into what helps older people who are living alone to combat isolation and loneliness - what personal strategies make a difference? A recurring theme connected to this was that of better public transport, and in particular better *community* transport i.e. accessible, affordable and acceptable
- Easier access to independent advocacy and counselling support services
- Ensuring there are personal development plans for older people who have ongoing mental and physical health needs, who need a lot of support either at home or in supported accommodation e.g. in residential or sheltered housing

Social inclusion and participation

“Not to accept that being old is being on the shelf... being part of society”

All of the themes in this report are essentially about creating a culture of understanding, equality of opportunity and opening up of life choices. *Citizenship* is a concept that is increasingly well understood in terms of improving opportunities for the participation of older people in their communities. It is less well understood or applied for those older people ‘on the margins’ (or in the shadows), in particular: older people with mental health difficulties; those who are homeless; and those who live in care homes.

⁸ Audit Commission and BGO reports ‘Independence and wellbeing: The Challenge for Public Services’ 2004 available at www.audit-commission.gov.uk/olderpeople/olderpeoplereports.asp

The importance of better opportunities for older people with mental health problems to contribute to local developments and community life was a central theme of discussions. This is not as common, especially for those with severe, enduring and degenerative conditions, as it is for other groups, including younger adults with mental health needs. A range of ideas for combating social exclusion were identified.

Increasing social inclusion

- Older People’s Champions’ could have a clearer role in raising a more positive profile for older people’s mental health, and in working together to combat the discrimination and stigma of mental health and age
- Raise mental health as a key issue at all older people’s forums and local groups
- The need for community learning projects that harness local resources and networks to better support the inclusion of older people with mental health needs
- More creative opportunities for older people with mental health needs to live *within* local communities with a range of support mechanisms to facilitate this
- Access to and use of local amenities, community centres and other facilities that offer an ‘open door’ and a safe place to be. To be part of ‘ordinary life’, to maintain and develop social networks, friendships and activities. These not only help the individual, but foster greater understanding and tolerance in communities
- Expand the creative use of new technologies. Examples included improving access to the use of computers, internet, email and chat rooms; as well as SMART technology to support people in a range of environments where control lies with the older person (a feature of the Gloucestershire SMART house⁹)
- Raise the profile and priority of people who live in care homes, to reduce isolation and to promote citizenship, a sense of purpose, feeling valued, ability to feel anger, and to have fun
- Make explicit and share the contributions that older people make as active and equal, valued citizens, for example the Mood Project in Scotland¹⁰; the Common Room in Warwickshire¹¹; The Sanctuary in Cornwall¹²

The analogy put forward by one group was that of “*building social capital*” as a way of harnessing and using all community resources - human and physical - in order to support all citizens and to create a more inclusive society.

“To be really heard and my needs met”

Participation in policy, service and community development is central to social inclusion and citizenship. The inclusion and greater participation of older people with mental health problems needs to be addressed, with equal and active participation as the norm, not just given lip service. Consultation should be part of the whole process not merely an end in itself. Participants emphasised that policy makers need to hear and act on the voices of people and not make assumptions about what they need or want - they must stop “*talking at them*”.

⁹ More information at www.healthcare.pervasive.dk/ubicomp2004/papers/final_papers/adlam.pdf

¹⁰ More information from Robert@moodproject.org.uk

¹¹ More information at www.ageconcernwarwickshire.org.uk

¹² More information from sanctuary@cornwallrcc.co.uk

“I have a right to my opinions without being laughed at”

The various forums that now exist to organise and disseminate the voice of local communities, patients, carers and others (e.g. Patient Advice and Liaison Service [PALS]; people’s panels; Patient and Public Involvement (PPI) forums; user groups) do help to increase the profile of diverse experiences and give weight to these perspectives. However, older people with mental health needs are still largely excluded from participating, not least because they are delivered through one main mechanism – meetings.

Older people with mental health problems may need support, time and patience to become involved and engaged, and to participate. This means that, for the short to medium term at least, more needs to be done to support and facilitate people to become and remain more vocal and influential. This needs to be addressed and owned by all Government departments, local, regional and national public sector agencies, voluntary organisations and older people’s forums.

BGOP and its Older Peoples’ Advisory Group, as part of the MOOTS partnership, is seen as central to developments that seek to improve opportunities and experiences of participation for older people. It was acknowledged, however, that these opportunities still tend to be limited to older people who are in good mental health.

Participants provided a wealth of good practice to increase the number of people who have a ‘voice’. Below are examples of the *principles* and *practicalities* of participation.

The principles of participation

- What is essential is commitment to, and understanding that participation is a central component of sustaining good mental health in later life. Professionals must be supported to think in new ways and to listen to the ‘expert’ older person
- A central principle underpinning all methods of participation is that of ‘outreach’ - going out to people, not waiting for them to come to you. Service users and carers need to be asked about their preferred methods of being involved
- Move beyond the mantra of engagement and involvement being difficult. Processes must be simple and transparent to ensure they are welcomed rather than avoided
- The use of skilled, sensitive and trained advocates is required to support people to take part, and to present the views of those older people with mental health difficulties who do not want to or cannot attend events
- Value and invest in ‘one to one’ contact - train older people to connect with individual service users, carers and local groups who can work together over time
- Ongoing, supported and active user and carer forums should be knitted into the fabric of local systems of care for older people with mental health needs, to ensure that older people are involved in setting the agendas of the wider partnerships
- Consultation must be seen to be effective. This means that views are not just listened to but responded to, by following up after consultation

The practicalities of participation

- Ensure expenses are paid and transport is organised to enable people to attend meetings and activities, and that consideration is given to the ways in which people are valued for their contributions
- Only fully accessible facilities are used for gatherings
- Printed materials are accessible (e.g. large print, translated into different languages and dialects, in Braille etc) and produced in simple, plain language
- Keep both the format and content of consultations simple: too many complex issues dealt with at once is confusing and unnecessary
- Have a variety of methods or mechanisms for involving people and enabling them to have a voice, especially to help engage more marginalised groups (e.g. use of the arts). Learn from those who are already participating *now*
- Avoid the tendency to interact only with the same group of older people and find ways of including those often excluded, for example - set up groups in hospital settings, care homes and supported accommodation, and meet local minority ethnic groups in their own communities
- Activities are planned in such a way that participants are, and feel, supported. Those people who do the involving and engaging need training and guidance to ensure excellent facilitation skills
- Explore the co-facilitation of events with older people *“Only older people can speak for older people; health and social care providers need to acknowledge this”*

Options and opportunities to increase choice and control

The need to increase the range of options for support, which reflect *individual* choice as well as the nature and level of individual needs, were at the heart of participants’ aspirations. This was often the reason why so many people were frustrated with the way current services are organised and delivered - the consideration of service structures and availability but not attitudes, accessibility and flexibility.

Alongside the notion of choice and control was the need for different kinds of enabling guidance for those who need and want it, to help them navigate these options and to make these choices. One approach for enabling people to live inclusive and fulfilling lives, which is now embedded within national policy for Learning Disabilities, is ‘person centred planning’.¹³ The Older People’s Programme are currently exploring ways of adapting this approach, through a Department of Health funded project called ‘Circles of Support’. The lessons from this work will be fed into MOOTS.

Greater attention needs to be given to the ideas of choice and control in future policy and practice developments. The messages related to this theme are captured below.

¹³ Valuing People: A New Strategy for Learning Disabilities for the 21st Century, Department of Health, 2001

Widening opportunities that increase choice and control

- Greater, more meaningful involvement of older people with mental health needs in their own care; in strategic planning and developing and reviewing local services
- Advocacy and self advocacy, including the support to take risks
- Mechanisms and cultures that encourage and support older people to be actively involved in decisions about their own care, and encourage people to explore self help and self management
- Older people delivering services for older people, including user run services
- We need to see more older people, including those with mental health needs, acting as mentors and trainers to professionals e.g. to nursing students
- We need to learn about which approaches do and do not work - to try out different ideas e.g. through a development programme or network of local learning projects
- The need to develop 'half way' houses and more creative options for emergency or 'critical care'; people with mental health problems may at times have greater and lesser needs and will require different responses – like anyone of any age
- The need to develop supported accommodation that is shaped by people's preferences and ideas (e.g. an 'Outrageous Women's Home'!)
- Person centred planning and 'circles of support'
- Carefully adapted and monitored systems of Direct Payments
- Shifting power and control away from statutory services to communities and individuals – with support, guidance and commitment from statutory services
- Reframe the performance management arrangements that drive systems, to ensure that older people are defining standards and setting meaningful targets
- Learn from disability lobby groups and translate these lessons to meet the specific circumstances and needs of older people with mental health problems

4.2 Services and delivery

Developing responsive, person centred services

"knowing the person the disease has"

Participants emphasised that an understanding of quality of life must be embedded in the person-centred services and systems that respond to individuals' needs. There is a need to re-learn the basics of what helps, such as the importance of reliable routines, human interaction and trust, stimulation and purpose, and to build support systems based on these principles.

Also vital is 'continuity of services', indicated by the fact that people can move between services as and when the need arises, when their circumstances change. This requires co-ordination of services and practice responses to underpin a holistic approach within health and social care.

Performance management and the regulation of statutory and non statutory agencies must shift to reflect a far greater value placed on the human face of services and the importance of seeing the person first and the illness second. Below are examples of these approaches and ideas for the action needed to develop them.

Person centred services and systems: examples and actions

- Improve links between primary, secondary and voluntary care services and staff, for example through multi-agency, inter-disciplinary training or planning events
- Quicker access to appropriate staff and services earlier on, in the first stages of a degenerative illness or deterioration. This will only come about when there is a shared belief in empowerment and prevention, to support older people with mental health problems, rather than 'containment', protection and minimising risk
- Accurate diagnoses and assessment that actively involve the individual; lead to forward looking and individually tailored care plans and interventions, including rehabilitation; and respond to degenerative conditions e.g. dementias
- Clear, appropriate and flexible pathways through the service system that are known and understood by everyone involved, to ensure coordination
- Greater attention to, and a better understanding of, effective commissioning requirements and arrangements, across the range of public services involved
- Scope and collate good practice to achieve a comprehensive system of support and opportunities, and learn from innovative examples e.g. developments in rural areas to support isolated people transposed to inner city areas for isolated people. This in turn will help us gain a better understanding and wider knowledge of the factors that influence the mental health and wellbeing of older people
- Need further research to identify examples of effective mechanisms and partnership arrangements for 'person centred' commissioning and service delivery
- Develop a shared and practical understanding of what a good, comprehensive system of support for older people with mental health problems looks like and feels like - for service users, for carers, for practitioners, for managers and commissioners, for policy makers, and for local communities
- Focus on 'humanising' services by examining different models of care delivery and shared care arrangements
- Address the lack of psychological and emotional support for older people, via access to community centres, counselling, and places where people can unburden themselves; to more sophisticated therapeutic interventions (e.g. Cognitive Behavioural Therapy)
- Eliminate age barriers for receiving support and accessing interventions, by ensuring mental health is part of local age discrimination audits, and by addressing the two tier mental health system that exists for those under and over 65
- Have a clearer, more explicit stance about improving mental health and wellbeing in older age rather than the current Government Policy emphasis on earlier stages of life (e.g. what happens to 'working age adult mental health services' when the retirement age increases? Or if people have been long term unemployed?)
- Nurture the visionary and enthusiastic leaders and leadership styles that have been identified as key to this work
- Focus on changing attitudes so that all mental health needs are recognised, understood and addressed, by pulling together all interest groups to improve communication and achieve greater coherency
- Explore the greater use of the Health Act Flexibilities, the partnership arrangements within Section 31 of the Health Act 1999, and other models of partnership and integrated working to share resources and commitment
- Greater transparency about procedures, protocols, systems, and how they work or don't work to support older people with a range of mental health difficulties

Locally based and locally delivered care

When participants shared their *positive* experiences, the importance of locally based services and people was a clear message. Services need more and better involvement of older people, *including* those with mental health needs, in determining and designing the types and levels of community support required.

Within each locality, greater attention to and understanding of the needs and aspirations of different communities, and the diverse situations in which older people live, is required to shape local services. There is a need to develop further understanding about ethnicity and mental health in later life, and ensure that 'inclusive' really does mean everyone. Examples are captured below.

Improved and increased access to locally based care

- Primary care practitioners, especially GPs, need to be better trained about mental health problems in mid and later life, including assessment; access to specialist help to make diagnoses; early intervention; treatment and support options
- Professionals, and others involved in supporting older people, need to be more mindful of the wider determinants of good mental health - what helps develop and retain a sense of wellbeing, illustrated in Figure 1 on page 20
- Accessible information about what support and services are available in the local community and how to access and use them, including carer support and respite
- Older People's Champions – who already exist – could be engaged in addressing these issues in their localities, to promote an holistic, citizen-centred approach for improving and protecting older peoples' mental health and wellbeing
- The need for a unified focus on supporting and enabling older people with mental health needs to have opportunities to contribute, to have a role and purpose to life and within their communities. This requires approaches from organisations that support risk-taking in line with what matters to the individual – and don't seek to blame when things go wrong. This will require skilled and experienced leaders
- Everyone involved in implementing the NSF for Older People in a locality to promote 'active ageing' that encompasses good mental health and wellbeing, and to ensure that implementation emphasises health promotion and inclusivity
- Need further scoping work and research to learn how local implementation of policies and guidance around the development of mental health services for older people is progressing (especially standard 7 of the NSF for Older People)
- Focus on building flexible support services and options at a local, community level – with less planning and deliberation, more doing and seeing what happens
- Need interactive partnerships between statutory and non statutory agencies, local staff, service users, carers and volunteers e.g. regular meetings in local areas, and wider partnerships organised around communities. Local forums, businesses and associations also need to be engaged e.g. village halls, parish councils, local clubs
- Increase opportunities for non-professionals to use their knowledge and skills (some may need support and training to do this) to assist older people to remain independent. E.g. information given to older people by care assistants, 'meals on wheels' volunteers, home care staff, care home staff
- Need to consider the local services and amenities that become difficult to access if mental health deteriorates e.g. transport, chiropody, financial help

Training and workforce development

Participants emphasised the importance of training in its widest sense – learning, support and development for all staff, especially those working outside specialist services. Training must focus on the humane and wider aspects of ensuring good mental health, as well as a wider range of approaches for supporting people with mental health problems. Medical staff and GPs in particular were singled out as a priority group for raising general awareness, as well as more specific training around mental health and later life.

Specialist training is needed for people working across all mental health services to address the wider determinants of mental health in later life, and to focus on learning from the experience of older people with mental health needs. Professional associations need to be targeted to ensure that pre-qualifying training as well as post graduate and qualifying courses address these areas. Professional journals need to be targeted to access practitioners and researchers. Other ideas are outlined below.

Developing staff working with older people with mental health needs

- Valuing staff working in all services and sectors, especially those who are lowest paid and less visible
- Increasing time for staff to learn about what mental health means in mid and later life; about the impact of mental ill-health; and how to *enable* rather than *disable* older people with mental health problems
- Encourage specialist staff to be enablers, to educate older people and local communities, and other staff working within mainstream services

One way of beginning this initiative, would be to harness the enthusiasm and support of groups that already exist (such as the British Geriatric Society's Specialist Interest Group on Cerebral Ageing¹⁴).

4.3 Wider national influences

Government influence and action

Participants identified key messages that involve Government, national as well as local, and increasingly regional bodies. This referred to policy makers and implementers across different government departments, including *but not solely* the Department of Health.

Suggestions for action that involve Government

- Mental Health legislation that encourages and reinforces inclusion and human rights
- Equitable and more creative resource allocation
- Encouragement and empowerment of local and regional services to adapt and improve their approaches and systems
- A stronger voice for voluntary and community organisations working in this arena
- Social Services Departments need to be, and to feel, accountable
- A clearer policy and practice direction that focuses on person centred approaches, inclusion, and quality of life - with performance indicators based on these rather than on organisational arrangements
- Investment in visionary and enthusiastic leaders and leadership
- BGOP to have greater influence across Government departments, with regards to promoting the citizenship of all older people

¹⁴ More information at www.bgs.org.uk/sigs/cerebage.htm

Raising awareness using media and education

“Society will celebrate ageing”

The lack of awareness and understanding about mental health in later life was a dominant theme. This message was strongly delivered by older participants who experience the impact of the negative stereotyping within the media, especially those which perpetuate inaccurate and misleading images of frailty and hopelessness associated with old age and mental illness.

It was agreed that a focused and well organised media campaign is a crucial step towards changing how people see mental health in older age. There was commitment to engaging the range of national and local media in the agenda for change, to educate and campaign for better understanding and a more accurate portrayal of mental health and ill health in later life. Ideas to take this forward are outlined below.

Raising awareness and changing attitudes using the media

- Raising awareness and understanding of the central importance of mental health to the quality of life in later life, including education about the range of mental health experiences that may affect people
- Placing a greater emphasis on prevention and public health promotion
- Addressing the stigma of mental illness by dismantling myths and misunderstandings (e.g. do people know that depression in older age is treatable; that memory loss is not synonymous with dementia; that there is more than one kind of dementia; that dementia can occur at any age)
- Celebrating and sharing good partnerships and networks – to show what can be achieved, including at national level e.g. Mood Project to speak to the Stroke Association
- Wide use of local, regional and national media e.g. radio and press, to disseminate information and good practice to more people, including those who are isolated, housebound or live remotely – describing practical things that people can do, and publicising telephone helplines and further sources of assistance
- Engage the national broadsheets and tabloids, for instance, *The Sun* to run a major feature on dementia, depression and the empowerment of older people
- Influence the film and TV industry to portray ordinary older people with different mental health needs, including on soaps rather than ‘sensational’ documentaries

Chapter 5: Agenda for action: a MOOTS Learning Network

There is much work to be done individually and collectively by many different groups to take forward the ideas, actions and concerns outlined in chapter 4. However, we asked people to focus on what we - collectively - should be doing under the banner of Moving Out Of The Shadows (MOOTS). A ‘MOOTS Learning Network’ was the main vehicle identified by all who participated in the MOOTS event in 2003, and others who have since been approached to determine the level of support across the UK. The positive responses to this initial enquiry have been overwhelming.

The MOOTS Steering Group have developed the initial ideas, in consultation with some of the MOOTS event participants and with other potential partners, and have put together a plan for establishing and facilitating a MOOTS Learning Network. The Network would be managed by the MOOTS Steering Group, and the plan is now being pursued by the Steering Group to ensure this vital venture is achieved over the next six to twelve months.

The MOOTS Steering Group has grown to encompass a number of major national partners over the last year. It now consists of co-chairs from the Older People’s Programme (OPP) and Better Government for Older People (BGOP), plus members from UK Older People’s Advisory Group (OPAG); Help the Aged; the Local Government Association; Association of Directors of Social Services; Policy Research Institute of Age and Ethnicity (PRIAE); Trafford Primary Care Trusts; Cambridgeshire Social Services Department; and Community Service Volunteers. The Steering Group has developed an agenda for action focused initially on securing funding and establishing mechanisms for running the MOOTS learning network.

5.1 The purpose and aims of the MOOTS Network

- To focus on greater inclusion and quality of life for older people with mental health needs – defined by their experiences, views, aspirations and participation
- To achieve the above through a commitment to share and learn from what works and helps to make a positive difference. This includes sharing of information, of good practice, of different ways of working, of views and experiences, and of opportunities and new possibilities
- To educate and inform - public policy and practice, Government policies for and beyond health and social care, local developments, and wider attitudes and beliefs about age, ageing and mental health
- Promoting older people with mental health needs as citizens and partners in all of the above

5.2 Clarifying the location of the Network within BGOP/OPP structures

- The Network will reflect the shared aims and values of BGOP/OPAG and OPP as co-chairs and facilitators of the Network
- The Network will be hosted by OPP, but jointly managed and facilitated by BGOP/OPP with the help of the MOOTS Steering Group
- BGOP/OPP will report directly to the MOOTS Steering Group who will act as the key governance body

5.3 Specific topics to be addressed by the Network

- Effective and acceptable methods of involvement and engagement for older people with mental health needs at all levels of policy making, implementation and in practice and service delivery

- Mental health promotion/public mental health and preventative aspects that fall under the broad term of 'promoting independence'
- Social inclusion using a range of community development/participative approaches
- Public awareness and education around mental health and mental ill-health in later life (including staff)
- Combating age discrimination and ageism in mental health

5.4 Methods/process of operation for the Network

- The Network will use a variety of interactive and participative methods including large and small events; regional and local meetings and discussion forums; occasional papers; newsletters; website and email exchange; the use of local, regional and national media and new technology
- This mixed methods approach will both encourage and harness the contribution of different perspectives, backgrounds and experiences – whilst also building and establishing common goals and shared values for this work
- The Network will be concerned with demonstrating both “what” and “how” improvements occur e.g. through the case studies and local learning projects

5.5 Benefits/services for Network members (“what you get for joining”)

- Access to a mix of events: one annual national conference; minimum of two regional roadshows/workshops/seminars; topic-based occasional gatherings
- Briefing papers and sheets on specific topics and policy updates
- Electronic links - discussion boards/forums, email group etc
- Newsletters; special feature pages of Stratagem and other publications
- Becoming part of the wider network and web of links of the MOOTS partners (BGOP/OPAG, OPP, Help the Aged, LGA, DoH) and BGOP Alliance Partners
- Access to other 'mainstream' events: BGOP annual meeting, OPP seminars and workshops, etc
- Feeding into the governance arrangements for mental health in later life - via direct links with DoH, DWP, ODPM, LGA, ADSS
- Access to expertise and experience in local/regional developments taking place in mental health services for older people across the UK

5.6 Who the Network is for (who would be able to join the Network)

- Individual older people
- Carers
- Practitioners (including managers)
- Any public sector agency
- Any voluntary organisation
- Independent/private organisations
- Professional associations/colleges
- Consortia of public and private agencies (e.g. Local Strategic Partnership, and other local partnerships established for this purpose)

Appendix 1:

Older People's Programme briefing paper: mental health services for older people

This paper was written in December 2002, as part of the background to planning and establishing the MOOTS partnership, and demonstrates the context within which this first MOOTS event took place. It should be noted that much is starting to change, in terms of the recognition and profile that older people's mental health services has now achieved in the policy and practice world.

Setting the scene

Mental health problems are a major cause of ill-health, disability and mortality at all ages. The White Paper, *Savings Lives: Our Healthier Nation* (DoH 1999) summarised the main types of mental health problems under the following classifications:

- Depression and anxiety
- Schizophrenia
- Dementia
- Bipolar affective disorder
- Antisocial personality disorder

People with mental health problems often suffer considerable distress, fear, isolation and social exclusion. For older people, the social consequences of mental health problems can further increase the stigma and social exclusion they experience, affecting the opportunities they have, and are able to exploit, to play an active part in everyday life.

People aged 65 years and over make up a fifth of the UK population and this proportion is growing. In 1996 there were 5000 centenarians; by 2016 this number is predicted to rise to over 20,000 (Forget Me Not, Audit Commission, 2000).

Many older people do not need support from health or social care services, yet older people use approximately half of all health and social care services and account for two-thirds of emergency medical admissions to hospitals.¹⁵ Many of the current government's policies for care services and the broader inter-ministerial initiatives such as Better Government for Older People, are aimed at improving the quality of life for older people and reducing inequalities in health. What older people themselves want is the opportunity to live independently, as full and active citizens in control of their own lives.¹⁶

Six per cent of people aged over 65 years are likely to experience some form of dementia and this incidence rises to around 20 per cent of people for those aged over 85 years. At the same time, it is estimated that around one-quarter of people over 65 years suffer from depression, with 15 per cent experiencing severe mental illness requiring some form of treatment. Because of reported problems in detecting and diagnosing mental health problems experienced by older people, it is likely that these figures are under-estimates – especially for depression. Until recently this group had received relatively little – both in terms of resources and a national policy direction.

¹⁵ *Shaping The Future NHS: Future planning for Hospitals and Related Services*, Department of Health, 2000.

¹⁶ *A Life Worth Living*, Tessa Harding, Help the Aged, 1997; *Living Well in Later Life*, Nuffield Institute for Health 2002

The national policy context for mental health

There are a number of themes running through wider governmental policy which also inform mental health policy. Much of it is intended to address the structural causes of ill health and to lay the foundations of a healthy society in Britain. The key themes are:

- Tackling social exclusion
- Reducing inequalities in health
- Promoting health and tackling the root causes of ill health
- Integrating care - the importance of partnerships
- Providing care closer to home
- Shifting from secondary to primary care
- Patient and public participation

Current mental health policy echoes these key cross-cutting government policy themes, heralding significant and comprehensive changes in developing and delivering services and support arrangements.

The NHS Plan (DoH, 2000) and the Mental Health National Service Framework (NSF) (DoH, 1999), outline new ways of working and new models of service delivery for people with mental health problems. The NHS Plan outlined additional investment in secure beds, 24 hour staffed beds, extra assertive outreach teams and improving access to services 24 hours a day, 7 days a week. The NSF built on Modernising Mental Health Services (DoH, 1998) to set 7 standards, which are comprehensive and have implications for action at all levels and across a broad range of organisations. These standards address:

Mental Health National Service Framework

- **Mental health promotion** and tackling the discrimination and social exclusion associated with mental health problems; (Standard One)
- **Primary care** and access to services for anyone who may have a mental health problem; (Standards Two and Three)
- Effective services for people with **severe mental illness**. (Standards Four and Five) This includes the requirement that Care Management and the Care Programme Approach (CPA) should be integrated and outlines expectations of a range of services including:
 - Help with skills and social networks to address social isolation;
 - Help to access employment, education and training;
 - Assistance with daily living;
 - Supported living, with flexible support so more can be provided at times of crisis
- Individuals who care for people with mental health problems. It requires **carers** who provide regular and substantial care for a person to have an assessment of their own needs and a care plan; (Standard Six)
- The action necessary to achieve the target to **reduce suicides** as set out in Saving Lives: Our Healthier Nation. (Standard Seven)

The implementation guidance for the Mental Health NSF (DoH, 2001), emphasised the need for whole system development, and provided detailed information on the different components that such a system should comprise:

- **Crisis resolution team/home treatment teams** to act as a gatekeeper to mental health services and provide immediate multidisciplinary community based treatment 24 hours seven days a week for individuals with acute severe mental health problems
- **Assertive outreach service** to support people with severe mental health problems with complex needs who have difficulty engaging with services and often require repeat admissions to hospital
- **Early intervention** in psychosis to provide evidence based interventions and promote recovery during the early phase of psychotic illness
- **Effective partnerships** between primary care, health, social and voluntary sector provision to ensure effective treatment and faster access to people with a range of mental health problems
- **Primary care** – new workers and new ways of working to provide an effective response to a range of mental health problems
- **Mental health promotion**

Additional guidance has since been published, including specific guidance on community mental health teams, acute in-patient care, employment of people with mental health problems, a Strategy on Suicide Prevention and a Women's Mental Health Strategy.

All this guidance is relevant to this debate about the current picture of provision and development needs for a more coherent and broader strategic vision for improving the mental health and wellbeing of older people.

Yet, we know from experience - and from talking to a broad group of interested and involved people - that older people often do not have access to the range of supports and specialist interventions outlined above. Furthermore, the emphasis on enhancing opportunities for users of mental health services to determine the shape of their own care arrangements, and the development of national as well as local policies, has focused largely on adults of working age (under 65 years). The experiences, contributions and participation of older people with mental health difficulties are significantly more limited.

The national policy context for mental health and older people

The lack of a profile for, and understanding of mental health in later life, is gradually shifting - mainly due to the impact of specific guidance such as the **National Service Framework for Older People** (Department of Health, 2001), **No Secrets** (Department of Health, 2000) and **Forget Me Not** (Audit Commission, 2000; 2002) and other, more general guidance outlined in this paper.

Advances in clinical practice and specialist research programmes undertaken by the Royal Colleges and professional associations, Dementia Services Development Centres (DSDCs) and the Mental Health Foundation, have helped to raise the profile of specialists caring for older people with mental health problems. They have also had a "lobbying" role that has successfully raised awareness about the range of mental health needs that older people may have.

Health and social care organisations are now required to demonstrate how they both identify *and* respond to the needs of older people with mental health problems, mainly through the milestones of the NSF for Older People (see below); previously via their Health Improvement Programmes and Joint Investment Plans (JIPs), and now Local Delivery Plans under the leadership of Primary Care Trusts. As this is a relatively new requirement for older people's mental health services, a tradition of reporting on these services has not yet fully developed. For example, a one-year study of JIPs identified that older people with mental health problems are rarely identified as a separate group in terms of service development and investment.¹⁷ It follows that resources have not been historically targeted at this group, whilst strategy development is still in its infancy in most areas of the country.

When asked about health care provision, the most commonly expressed desires of older people are: easier and earlier access to good information, advice and primary care.¹⁸ Support for carers, both family and friends, is another priority. Older people with mental health needs say the same thing – and yet this is often not reflected in policy and practice developments affecting specialist mental health services for older people. The links between mainstream public services and more specialist provision need to be strengthened and built upon to ensure local whole systems of care are developed around mental health services and support arrangements for people of all ages. The Audit Commission's reports on mental health services for older people¹⁹ highlight not only the importance of primary care but also the variability in primary care provision, especially for diagnosing and treating older people with mental health problems.

The National Service Framework (NSF) for older people

This NSF is the largest and most complex of the frameworks to be produced in England and Wales. It covers NHS hospital and community health services, the healthcare components of residential and nursing home care, as well as the transitions between these settings. It includes new, integrated service models for improving the care of all adults with stroke, dementia, depression and injuries sustained through falls. The primary focus is on frail older people, although the NSF also includes standards for disease prevention and the promotion of health and wellbeing, for palliative care, the relief of distressing symptoms and end of life care.

In addition to eight core standards and the service models referred to above, it addresses the interfaces between health and social care; both generally and more explicitly between primary and community based services and secondary, specialist services. All standards stress the key, sometimes leading, roles that should be played by statutory social services and primary care in the provision of care for older people. It is therefore both multi-agency and multi-dimensional in nature and intent. The core components of a high quality service for older people with mental health problems, synthesised from Standard 7, Mental Health in Older People, are illustrated overleaf.

¹⁷ *Joint Investment Plans for Older People*, Nuffield Institute for Health, 1999

¹⁸ *A life worth living: the independence and inclusion of older people*, Tessa Harding, Help the Aged, 1997

¹⁹ *Forget Me Not* (2000; 2002)

Mental Health in Older People: Standard 7 of the NSF for Older People

- Early detection and assessment, with primary care having a leading role
- Increasing emphasis on mental health promotion and prevention of ill-health
- Access to specialist services, advice and skills, treatment and rehabilitation - with an emphasis on provision at home and support for carers
- Care management, care coordination and treatment planning, including the translation of requirements of the Care Planning Approach [CPA] for older people with severe and enduring mental illness; and the implementation of integrated care pathways for dementia and depression
- Increased clarity about the roles and relationships between specialist services and teams, and generalist services including primary health and social care
- Continuous development from sharing good practice and learning from experience
- Services that anticipate and respond to the needs of older people from minority ethnic communities, and people with complex health and social care needs (e.g. with a learning disability)

A key feature of mental health service provision in the last five years has been the development of community mental health teams (CMHTs) and through them improved access to a range of supported domiciliary, residential and hospital based care. This has been slower within mental health services for older people than it has for working age adults and children's services. With an ever increasing focus on the ability (and capacity) to access specialist care and skills regardless of setting, and towards more care provided closer to home, CMHTs for older people are now seen as an essential feature of implementing the NSF for Older People.

An integrated, comprehensive system of care would therefore be underpinned by a focus on primary and secondary prevention and mental health promotion, early intervention and the provision of care closer to home. It would include the following key components through which this would be achieved.

- Locally based information and advice service(s) aimed at providing service users and carers with timely, accessible and useful information about the nature of different mental health problems and conditions, where and how to access further information, advice and specialist help
- Accessible and supportive primary and community based health and social care services
- Integrated community mental health team(s) operating at the interface between primary and secondary care
- Crisis and home treatment team(s) providing a range of therapeutic interventions at home or as close to home as possible
- Specialist home care services
- Access to diagnostic and therapeutic interventions, such as validation therapy and Dementia Care Mapping and community based rehabilitation
- A range of options for accessing and providing respite care
- Specialist in-patient assessment and treatment, where the numbers and location of beds are determined on the basis of local population requirements and the range and balance of services across the whole system of care
- A range of options for receiving long term care in different settings including at home, in supported and extra care housing, and residential and nursing homes

The roles and relationships between primary care, mainstream services and specialist mental health services for older people need to be discussed and agreed, and protocols for shared care and pathways for dementia and depression implemented. This includes agreed protocols for the management of people who have both physical and mental ill health, to ensure that care is given by or from the most appropriate service.

Timescales for implementing key action points and milestones within Standard 7 are longer than for other Standards in this NSF, reflecting the amount of work to be done nationally to address variations in provision, i.e. access to a comprehensive range of quality services across different boundaries.

Many local care communities have started to address the milestones summarised below, but most are at an early stage of development with regards to developing a whole systems approach across health and social care and across statutory and non-statutory sectors.

NSF for Older People Standard 7: summary of actions and milestones

NHS and Councils to:

- Review local systems of care, including health promotion
- Review current care pathways for depression and dementia
- Review same for young onset dementia

By April 2004:

- Hlms and JIPs to specify plans for developing integrated mental health service for older people, including mental health promotion
- Every general practice is using protocols agreed with local specialist services for dementia and depression
- Secondary care systems have agreed protocols in place for management of older people with mental health problems

This NSF has provided a much needed impetus for local agencies to drive through changes and system-wide improvements that should lead to greater consistency of quality service provision. It has not, as yet, contributed to local developments of “joined up” approaches in addressing the broader determinants of health and wellbeing, of which mental health is a key feature. Examples would include the importance of social networks, of good housing, an adequate income, access to leisure and learning opportunities, and affordable public transport.

An additional shared concern of the three organisations hosting this MOOTS event, is the tendency for policy milestones and targets to shift the emphasis from the person, to service and organisational plans, procedures, processes and protocols. The long “lead-in” time for these milestones has also meant that the focus on and resources for older people’s mental health services have often been diverted, as local agencies have concentrated on earlier milestones connected with intermediate care, the single assessment process and rooting out explicit indicators of age discrimination.

All of these areas do, of course, apply equally to older people with mental health difficulties. In practice, however, the focus both at a national as well as local level, has been upon the delivery of milestones affecting acute care and the organisation of teams and services that help people avoid the need for hospital admission (e.g. intermediate care, integrated falls services) rather than on exploring options for supporting older people with mental health needs differently and with a greater emphasis on prevention and primary care.

Key themes from a review of development work undertaken with mental health services for older people

The Older People’s Programme (OPP) (then based at Kings College London and currently based at Help and Care) has worked with a number of authorities and agencies across England on implementing Standard 7 of the NSF, and other policy developments for older people with mental health needs. Through this work OPP has recognised the limited focus on the general mental health needs of older people across health, social care and housing services.

Where there is some recognition, the emphasis tends to be on dementia, which is still more commonly associated with old age. Depressions are now believed to be as common as dementias in older people. Statistical evidence indicates that the incidence of anxiety, phobia and schizophrenia, which are not normally associated with older people, are as common in older people as for the younger population (Audit commission 2000). A study on mental health service provision in Scotland reported that 31% of admissions of older people to mental illness hospitals were categorised as schizophrenia, affective psychosis, non-psychotic depression or ‘other psychosis’.²⁰

Although the Audit Commission’s two publications “Forget Me Not” (2000) and “Forget Me Not 2002” (2002), identified concerns around the current delivery and provision of mental health services for older people, their focus was largely on dementia services. The SSI inspection of mental health services – *Modernising Health Services* (2002) concentrated on children and Black and Minority Ethnic Communities.

These major publications therefore reinforce the need to ensure that the range of mental health needs experienced by older people moves higher up the national policy and practice agendas, rather than the current tendency to focus on dementia alone.

An internal review of work on mental health and older people

With these issues in mind, three development consultants working with OPP on mental health services for older people, met to undertake a thematic review of projects and reports by a range of NHS agencies and Local Authorities. The review spanned fifteen authorities across England and a synthesis of good practice drawn from this work, information from contacts and networks of the OPP and published and grey literature.

The table overleaf presents the key characteristics identified from this review, in relation to both commissioning and delivery arrangements for mental health services for older people. This information will continue to be refined with Moving Out Of The Shadows participants, drawing on a much broader range of perspectives and experiences.

²⁰ Bowers, H -Developing Inclusive Mental Health Services for Older People, Mental Health Review, 2001, Volume 6 Issue 2.

Characteristics of mental health services for older people	Causes and comments
Isolation of services, for people using them and people working within them	<ul style="list-style-type: none"> ● Not connected to rest of system ● Policy vacuum ● Weak links across agencies/departments (e.g. specialist services, housing, PCTs, acute hospitals)
Lack of a robust, shared vision and coherent strategy for future development of services	<ul style="list-style-type: none"> ● Lack of strategic direction, especially amidst constant policy changes ● Lack of identifiable leadership and management ● Tendency to 'chop and change' rather than sustaining innovations and ideas ● Lack of information about needs/aspirations of local older population
Unclear commissioning arrangements	<ul style="list-style-type: none"> ● Lack of information about needs and aspirations of local older population for effective commissioning ● Services not maximising resources through partnerships and service integration ● Commissioning not driving service developments
Inconsistent patterns of and arrangements for care delivery	<p>Specific problem areas identified:</p> <ul style="list-style-type: none"> ● Referral/access to GP's inconsistent; ● Securing an accurate and timely diagnosis; ● Lack of early intervention; ● Limited role for liaison across specialities, services and sectors especially primary and secondary care; ● Lack of co-ordination; ● Underdeveloped case management; ● Inconsistent arrangements for care management & reviews; ● Underdeveloped involvement of service users and carers in decision making and care delivery; ● Health promotion, prevention work is limited; ● Carers support varies.
Need for stronger emphasis on developing person centred approaches and service systems	<ul style="list-style-type: none"> ● At home/in care homes/supported housing ● Opportunities for using and extending the use of person centred approaches limited e.g. Person Centred Planning & Circles of Support; Dementia Care Mapping; Poole Activity Levels (PALs) ● More examples in dementia care than other areas
Achieving a balance between generalist and specialist services	<ul style="list-style-type: none"> ● Caught up in debates about where services 'fit', rather than what they do and are for ● Skills gap in general services: lack confidence and basic awareness about range of mental health needs experienced by older people ● Specialist services too remote and isolated (see above)
Focus on structural rather than system-wide solutions	<ul style="list-style-type: none"> ● Services and systems stuck in structural considerations and searching for structural solutions to complex problems ● How to move on to create flexible ways of working to deliver person centred care?

Relative lack of strategic development in sharing resources, and creating pooled resources	<ul style="list-style-type: none"> ● Continuing need to promote integrated working at all levels. ● Some examples of pooled/integrated systems which need evaluating and disseminating ● Encourage and support willingness to experiment/try new things – and learn from what works (for whom and why)
Developing a flexible, valued and supported workforce	<ul style="list-style-type: none"> ● Maximising skills and mix of staff at all levels and all disciplines/backgrounds to deliver care flexibly ● Need to explore new roles and ways of working ● Need to skill up mainstream services to support people to maintain independence and to promote inclusion ● Need to explicitly value and support staff working in all parts of the care system, at all levels ● Low energy and inertia in many places – initiative not recognised or encouraged ● Staff working in difficult situations – not always recognised or supported ● Development & leadership gaps ● New integrated teams need a lot of support
Low profile for and understanding of functional mental health problems	<ul style="list-style-type: none"> ● Inequity of provision <65> (e.g. often no access to advocacy and assertive outreach services) ● Lack of investment: resources mostly into specialist dementia teams ● Lack of recognition/understanding in mainstream services ● What pool of research/advice is available to people to give them confidence about what they are providing or developing?

This quick analysis led us to believe that a number of key strategic issues are not yet fully recognised and addressed with regards to the future development of and investment in whole systems of care for older people with mental health difficulties.

The following pages therefore summarise a number of recommendations and practical development strands that we have identified with colleagues from across the agencies with whom we have worked, and whose services were included within the thematic review.

Summary of key components for developing whole system, integrated service strategies for older people's mental health services

1. There is an urgent need to ensure that every area has agreed and articulated an integrated commissioning strategy and implementation plan for improving the mental health and wellbeing of older people, as well as for developing the *specialist* mental health services that they use. Such strategies should be underpinned by clearly stated shared values and a philosophy of service provision that is person centred, based on a notion of citizenship and the broader determinants of health and wellbeing. These determinants extend beyond health and social services to encompass housing, transport, the environment, pensions and income, leisure and other community facilities, lifelong learning, community safety and social networks.

2. Strategies should map out and describe the range of services and support systems that *should* be in place against those that are currently available. They therefore also need to encompass an agreed implementation and investment plan across NHS and Local Authority agencies, specifying how the desired service system and model of care provision will be developed over a specified timescale - ensuring that older people with mental health problems have access to and receive the information, advice, support, assessment, treatment and care, that they need and want to retain their independence, wherever they live.
3. Strategies should establish the overall aims of, and mechanisms for creating and sustaining a focus on primary and secondary prevention, mental health promotion, and early intervention for older people with a wide spectrum of mental health needs across functional problems and organic conditions.
4. In particular, strategies should emphasise the need to develop, build and sustain capacity within and across primary and community based services and supports - including locally accessible gateways to specialist, secondary care services.
5. If services for older people across the spectrum of needs, conditions and service requirements are to be integrated, equitably invested and developed, stronger links need to be forged with the wider world of public service improvement and citizenship for older people – for those who have mental health needs. Links also need to be maintained with mental health services and systems.
6. However, the greater need is to recognise that this arena straddles many worlds and many agendas; and that there are opportunities as well as practical difficulties associated with the multiple policy and practice fields that these services span.
7. One area that requires further investigation and planning is the potential for maximising locally based facilities that are being developed for intermediate care and respite services – to explore whether these facilities can be used as a service base but also as a resource for all staff and teams working across different services for older people. For instance, integrated Community Mental Health Teams for older people; assessment and short term in-patient facilities; respite care beds; day services; welfare and benefits advice and information services.
8. The links and interfaces with adult mental health services and strategies also need to be mapped out and clearly defined within this aspect of the strategy - including arrangements and decisions made around the interfaces and joint working arrangements of working age adult mental health services and older people's mental health services.
9. At the same time, integrated service strategies should clarify and explain the purpose and function of *all* services and teams, including in-patient services and facilities within the broader spectrum of services available. This will need to include a staged improvement plan that attends to any current shortfalls and environmental difficulties experienced within in-patient services in the short term (a common experience) whilst progressing towards a modernised in-patient service in the medium to long term.
10. The future provision of inpatient services could fit within a locality model of care for older people, to ensure a focus on prevention, early intervention and care closer to home is sustainable; this requires further detailed work and consultation. One way forward would be to ensure much closer, operational as well as strategic links, are established with developments taking place within 'general' older people's services - as outlined above.
11. The development of a broader range of options for funding and providing long term care services and facilities needs to be a key element of any comprehensive strategy, encompassing: care at home, supported housing/accommodation; a wider range of options for day time support and respite care; increased options for providing ongoing support to older people with functional mental health problems at home or as close to home as possible; residential and nursing home care; and end of life care in all settings/facilities.
12. As well as setting out the key components and models of service provision, service strategies also need to specify arrangements for ensuring essential care processes are integrated, responsive and coordinated - i.e. referral, assessment (including how the Care Programme Approach - CPA - is managed within local single assessment processes), care planning, care management and care coordination arrangements - and the delivery of appropriate treatment, support and care services.
13. In addition, local implementation plans should set out planned responses for addressing specific issues and identified gaps across the whole system of care. These typically include the following major challenges and issues:
 - Identifying, understanding and responding to the range of **functional mental health needs** that older people experience through increased opportunities for day services and daytime support, home treatment and care, specialist in-patient assessment and provision, respite care and longer term care in supported accommodation or residential care;
 - Identifying, understanding and responding to the needs of older people with mental health needs from **minority ethnic communities**;
 - Improving access to and availability of timely and acceptable information and support mechanisms for **carers**;
 - Supported housing, including **extra care housing** services and resources, and local arrangements for implementing Supporting People;
 - Hearing the voices and experiences of, and **actively involving service users and carers** at every stage and level of service commissioning, service development, and care delivery;
 - Stimulating a higher profile and clearer role for the **voluntary sector and the network of lay and community groups** in relation to older people with mental health problems and their carers;
 - Understanding the needs of and responses for people with **early or young onset dementia**;
 - Exploring some of the issues and decision making processes around the **transition and interfaces** between working age adult mental health services and older people's services; and between generic older people's services and specialist services for older people with mental health problems.

Appendix 2:

MOOTS event organisers, sponsors and facilitators

- The **MOOTS Steering Group** designed the MOOTS event programme, the promotional materials and identified who should be invited to attend.
- The **Older People's Programme (OPP)** managed the event, involved colleagues and partners from across Wales, England and Scotland, wrote the background materials and coordinated the publication of this report.
- **BGOP and OPAG** ensured that their partners and members involved in promoting citizenship and inclusion for older people were invited and involved, even if not attending the event. BGOP contributed resources to hold the event, and continues to host and service the MOOTS Steering Group.
- **Help the Aged** promoted the work, identified key people to involve and invite, and contributed resources to hold the event.
- The **Older People's Taskforce at the Department of Health** contributed resources for the event, in particular to ensure this report could be published and widely circulated, to participants and others who could not attend on the day.
- **Leeds City Council** hosted the event, providing the venue and refreshments.
- **Centrevents** provided the event management.

MOOTS event group facilitators

- Mairi Maclean, Associate Consultant, OPP
- Ronke Azeez, Development Manager, OPP
- Richard Poxton, Associate Consultant, OPP
- Gill Heath, Help the Aged
- Cathy Traynor, UK OPAG
- Tom Owen, Help the Aged
- Kathryn Hill, National Patients Safety Agency

Appendix 3:

MOOTS Steering Group

- Helen Bowers, Director, Older People's Programme (OPP)
- Mervyn Eastman, Director, UK BGOP
- Cathy Traynor, Chair, UK OPAG
- Ronald Carter, UK OPAG
- Teresa Lefort, UK OPAG
- Roderick Knight, Independent Consultant, ADSS
- David McNally, Service Modernisation Manager Older People, Trafford PCTs
- Duncan Tree, National Development Manager, CSV
- Mairi Maclean, Associate Consultant, OPP
- Tim Hind, Advisor, Local Government Association
- Mark Howe, Commissioning Manager Older People, Cambridgeshire County Council
- Tom Owen, Research Manager, Help the Aged