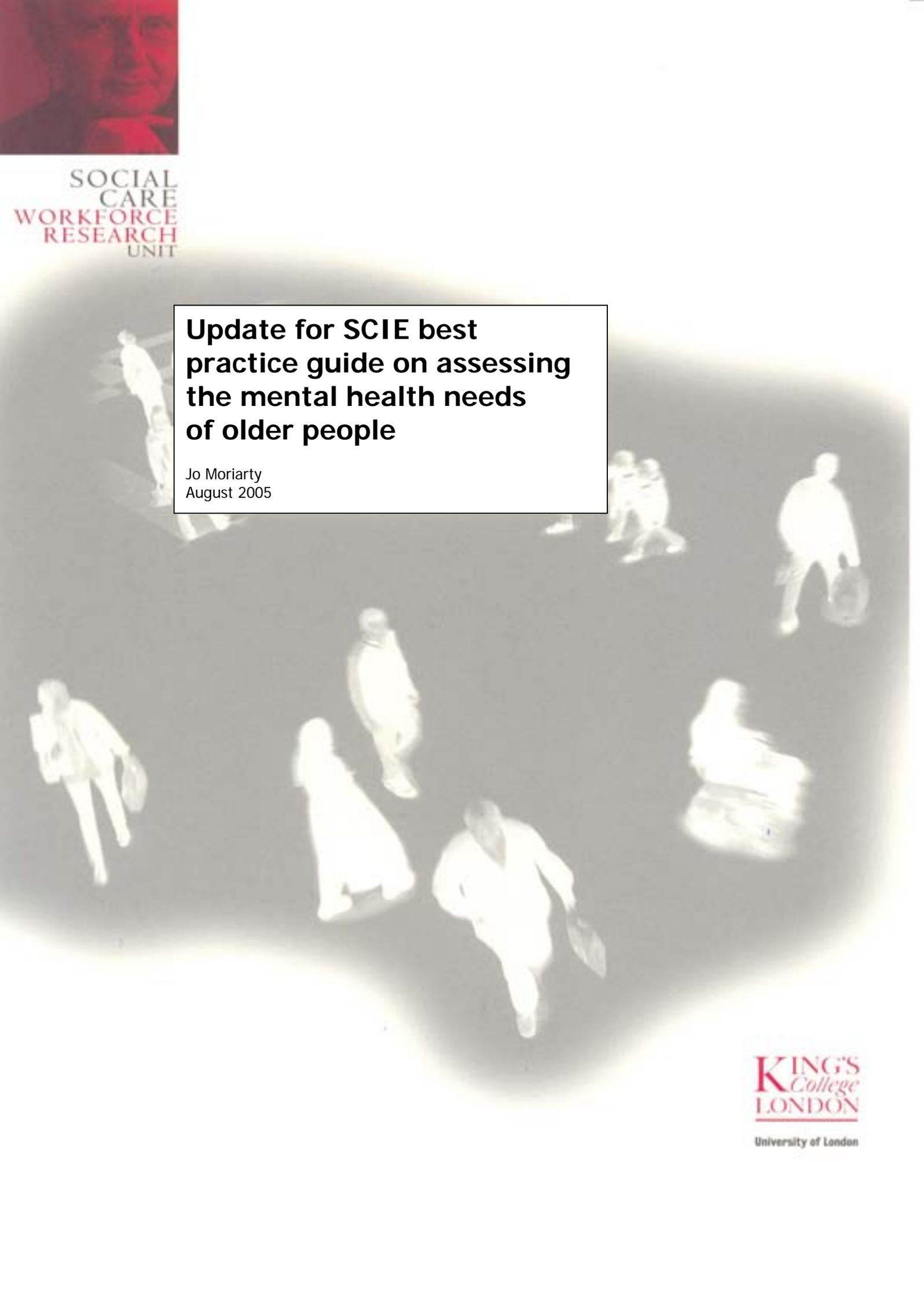SOCIAL
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Update for SCIE best practice guide on assessing the mental health needs of older people

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2. MENTAL HEALTH IN LATER LIFE: WHAT WE KNOW FROM RESEARCH

Summary

Although there is a substantial literature on mental health in later life, much of it has been driven by researchers and comparatively little has been based on the views of older people themselves. Nevertheless, there is consistent evidence that having a role, good social networks, an adequate income, and living in a supportive neighbourhood are important factors contributing to mental health in later life. Although there is increasing interest in how older people can improve and maintain their mental health, it is important that this is not simply concerned with how individuals can influence their mental health but also takes account of the wider social influences. Older people are an increasingly diverse group and current research now emphasizes the need to look at how mental health is influenced by the interaction of factors such as gender, socio-economic status, and ethnicity. However, despite advances in our ideas about the process of ageing, older people themselves still experience discrimination and older people with mental health problems remain a stigmatized group.

Mental health and well being

Everyone has mental health needs, whether or not we have a diagnosis of mental illness. There is increasing acceptance that good mental health is not simply about the *absence* of an objectively diagnosable disease but more about those aspects that are present, such as our sense of enjoyment in life (Seymour and Gale, 2004). Our mental health influences how we think and feel about ourselves and others, our ability to communicate and our ability to cope with change. Mental health may be central to all health and wellbeing because how we think and feel has a strong impact on physical health (Department of Health, 2001a). The term 'wellbeing' is generally used as a way of summing up how we feel about our varied life experiences (our health, where we live, our relationships and so on). Although the notions of mental health and wellbeing are clearly related, wellbeing is generally regarded as being more subjective in that there is a more explicit focus upon how we, as individuals, feel. Our sense of wellbeing is also felt to be less transitory than our mood, which is subject to change (Kahn and Juster, 2002). Early attempts to measure wellbeing presented it as being more or less synonymous with life satisfaction (McDowell and Newell, 1996). Later work has tended to emphasize its relationship to quality of life.

It is important to recognize that the majority of older people remain in good mental health. The chief difference between older people and other age groups is that older people are more likely to have experienced events associated with poorer mental heath, such as having to deal with a decline in physical health or bereavement. The term 'resilience' is often used to describe our ability to recover from difficult or stressful situations and it has

been suggested that our resilience is also likely to influence our wellbeing in later life (Kahn and Juster, 2002).

Health promotion in old age

Over the past 30 years, the notion that old age is inevitably associated with decline and disability has been effectively challenged (Phillipson, 1998) and it is increasingly recognised that steps can be taken to improve health and wellbeing in later life (Anderson, 2001; Seymour and Gale, 2004). Older people who take on active roles appear to have better mental health and wellbeing than those who do not (O'Reilly and Caro, 1994; Rozario *et al.*, 2004) whereas low levels of social engagement may act as a marker for later ill health (Bennett, 2002). In addition, physical activity may also contribute to improved morale and wellbeing, although the effects may be modest (Morgan and Bath, 1998) and may be more related to the sense of belonging engendered by physical activity with others (Bailey and McLaren, 2005). Furthermore, we cannot rule out the possibility that these results are influenced by selection bias, that is, only those people who are already in good health will take on active roles.

Such improvements to health in later life are seen as not only possible but also morally right. For example, the World Health Organisation describes 'active ageing' as the:

> *Process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age.*

> (World Health Organisation, 2002, p12)

'Active ageing' and similar terms such as 'healthy ageing', 'productive ageing' and 'ageing well' have been coined as a way of demonstrating the shift away from negative constructions of the experience of ageing. However, these concepts are not necessarily problem-free either. In particular, controversy has been attached to the term 'successful ageing' which was first used to describe the famous US-based MacArthur study of the factors that influenced physical and cognitive functioning (Rowe and Khan, 1997). The main criticism that has been made of this approach is that it fails to take account of the wider socio-economic structural factors that influence health. This may serve to marginalize older women, older people from minority ethnic groups, and older people living in poverty (Holstein and Minkler, 2003). Furthermore, conceptions of successful ageing have been dominated by western (specifically white US/British views) and have failed to take account of the culturally specific aspects of ageing (Wray, 2004).

Older people themselves have rarely been included in developing models of active or successful ageing (Knight and Ricciardelli, 2003). This has meant that tools and scales designed to measure wellbeing and mental health in old age have tended to focus on health, disability, and illness and omitted to

include aspects such as pleasure and autonomy that are important to people at all ages (Higgs *et al.*, 2003).

What older people say is important

It has been suggested that the effect of these conflicting debates about ageing is that older people themselves are caught between the medical model (sic) in which ageing is seen as a time of inevitable decline and the 'heroic' model whereby taking part in rock climbing and wind surfing is seen as a way of not 'giving in' to ageing (Reed *et al.*, 2003, p1). Based upon interviews with older people themselves, Reed and colleagues found that participants in their study saw healthy ageing as:

- adapting to continuous physical change;
- engaging in relationships;
- maintaining independence and taking risks;
- having adequate money;
- fulfilling desires and personal objectives; and
- keeping busy by taking part in meaningful activity

Similar findings have been reported elsewhere (Nazroo *et al.*, 2003; Audit Commission/Better Government for Older People, 2004). It is also important to note that where one aspect of a person's life is problematic, he or she may use another component of their lives to mediate the effects of these difficulties. For example, money to purchase aids and adaptations can be used to counteract the effects of a decline in physical health (Afshar *et al.*, 2002; Reed et al., 2003). In many ways, the way in which older people's definitions highlight the inter-relatedness of different aspects of ageing and their identification of ways in which strengths in one area can be used to counteract deficits in another arguably suggest greater complexities than have been shown by some researchers (Phelan *et al.*, 2004).

Social inclusion

The notion of social exclusion stems from European ideas about how society is best viewed as a series of collectivities, bound together by mutual rights and obligations. When members of society become detached from the systems of mutuality and reciprocities that constitute the social order, they lose their bonds with the rest of society. For some commentators, the effects of greater economic liberalism and neo-liberal policies in the 1980s and 1990s were to create areas in which disadvantages such as poor health, poor housing, high levels of crime and unemployment were concentrated (Jordan and Jordan, 2000). It is widely accepted that social exclusion in the UK rose during the 1990s. In terms of how older people have been affected by this, we see, on the one hand, increasing numbers of older people who have better health and material resources than previous generations and who are active members of the 'consumer society' (Gilleard and Higgs, 2000). On the

other, research undertaken in three deprived areas in Liverpool, Manchester and London suggested that significant numbers of older people in these areas were prone to different dimensions of social exclusion. These included:

- poverty;

- social isolation and loneliness;

- lack of civic engagement, such as taking part in community meetings;

- exclusion from basic services (for instance not using or economising on basic utilities such as heating or the telephone and not having access to services such as a local post office or chemist);

- neighbourhood exclusion, in terms of disliking the neighbourhood or fear of crime.

(Scharf *et al.*, 2003)

Although the research was undertaken in cities, this is not to say that only older people living in urban areas experience social exclusion. For instance, access to public transport and local shops is likely to be poorer in rural areas.

Ageism and age discrimination

Age discrimination is another factor that older people themselves see as contributing to social exclusion (Office of the Deputy Prime Minister, 2005). Although legislation to outlaw age discrimination in employment is promised by 2006, older people report that they also experience age discrimination in terms of access to health and social care, social security, education, in financial and retail services, and through their portrayals in advertising and the media (Help the Aged, 2004). The image of older people as a problem or burden in health and social care is widely held and it has wide implications for the way that services are delivered (Davison and Philp, 2003). Although the National Service Framework (Department of Health, 2001b) specifically aimed to outlaw age discrimination in health and social care, in practice, it is still thought to be widespread (Roberts *et al.*, 2002) There is concern that older people with mental health problems are especially likely to experience discrimination and stigma (Graham *et al.*, 2003; De Mendonça Lima, 2004).

Intersectionality

Earlier work in gerontology described the phenomenon of double and triple jeopardy whereby factors such as age and gender and age, gender and ethnicity combined to create a situation of multiple disadvantage (Norman, 1985). Recent research presents a more complex picture. Rather than treating the effects of factors such as socio-economic status, age, gender, sexuality and ethnicity as *additive*, in which the effects of each one is added to the other, there is increasing interest in examining how they *intersect* to create advantages for some and disadvantage for others (Calasanti, 2004). For example, the effects of marital status upon access to material resources in old age varies between men and women, with married men being most

financially advantaged (Arber, 2004). It demonstrates that, although some groups are more privileged than others in their experience of ageing, very few people are privileged on all dimensions (Calasanti, 2004).

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3: MENTAL HEALTH PROBLEMS IN LATER LIFE: WHAT WE KNOW FROM RESEARCH

Summary

Depression is the most common mental health problem among older people, followed by dementia. One of the most important issues for older people's mental health is the delay that regularly occurs before they are offered support. These happen either because of people's reluctance to seek help or under recognition on the part of professionals. This may have potentially severe consequences. People may end up with a lower quality of life because they have not been given the right sort of help or, where treatment options are more limited, people are not given the opportunity to have enough time to make important decisions about their future. Although there is greater awareness of the number of people with a learning disability or enduring mental health problem living into old age, there is still very little research evidence on how they can best be supported.

Dementia

Dementia is a general term used to describe deterioration in intellectual performance in terms of memory, language, orientation and judgement from a previous level accompanied by a decline in personal and social functioning. Other causes for this deterioration must have been eliminated. Over the past twenty years, definitions of dementia have become much more precise about the clinical features by which it should be identified and there is greater understanding of the different subtypes of dementia that exist. Of these, Alzheimer's Disease accounts for 50-60 per cent of all the people affected and vascular dementia and Dementia with Lewy Bodies each account for between 10-15 per cent (McKeith and Fairbairn, 2001). Mixed dementia, whereby a person has both vascular dementia and Alzheimer's Disease, is thought to be more common among the oldest old (Langa *et al.*, 2004).

How many people have dementia?

Although it is important not to forget that there are around 20,000 people with young onset dementia in the UK (Harvey, 1998), the overwhelming majority of people with dementia are aged 65 and over. After the age of 65, the risk of dementia doubles with every five years (Jorm *et al.*, 1987). This means that while 1.4 per cent of those aged 64-69 have dementia, the prevalence (that is, the number of people in the population who are affected) rises to 4.1 of those aged 70-74, 5.7 of those aged 75-79, 13 per cent of those aged between 80-84 and 21.6 per cent of those in the 84-89 age group (Hofman *et al.*, 1991).

Although only a minority of older people living in the population as a whole have dementia, a high proportion of those using community (Livingston *et al.*, 1997) and long term care services (Mozley *et al.*, 2000; Macdonald *et al.*, 2002) are affected (see Section 7).

What causes dementia and can it be prevented?

It is not known precisely why some people develop dementia while others do not but it is likely that it results from a combination of reasons. People who have suffered head injury are more likely to develop dementia (Gedye *et al.*, 1989; Fleminger *et al.*, 2003). The number of people developing vascular dementia might be reduced by efforts to reduce stroke and hypertension (Haan and Wallace, 2004; Majeski *et al.*, 2004). Although there has been some suggestion that the consumption of omega-3 fatty acids and food supplements might help improve cognitive functioning as people age (Whalley *et al.*, 2004; Solfrizzi *et al.*, 2005), there is not yet enough evidence to know whether this is the case (Maclean *et al.*, 2005; Morris, 2005). Moderate amounts of wine may be beneficial (Pinder and Sandler, 2004) but excessive amounts are associated with brain damage. Increasing attention is also being given to the idea of 'use it or lose it' (Coyle, 2003). Rarely, as for instance in the case of frontotemporal dementia, there are genetic reasons why a person develops dementia (Mack *et al.*, 2001; Morris, 2005).

The importance of early diagnosis

Alzheimer's disease and other forms of dementia often remain undiagnosed until symptoms become moderate or severe. This delay may occur because of the:

- difficulty of recognising the symptoms of early dementia;

- attribution of symptoms to so-called normal ageing;

- fear of dementia that is common among older people; and

- use of inadequate screening tools and/or a delay in the confirmation of the diagnosis once suspicion is raised.

(Bond *et al.*, 2005)

Although there has been controversy about the helpfulness of early diagnosis (Iliffe and Manthorpe, 2004), the arguments in its favour are that it eliminates the possibility of a reversible reason for the deterioration (for example, infection, adverse reaction to drugs), it may come as a relief to the person who can understand what has been happening to them, it can help with long term legal planning and day to day decisions such as continuing to work or drive a car, and there is a possibility that the person will benefit from cholinesterase inhibitors (Brodaty, 2005). There seem to have been improvements in GP's attitudes to early diagnosis (Milne *et al.*, 2005), an important factor because of their pivotal role as gatekeepers to health and social care services (Iliffe, 1997). Although it has become more common to share the diagnosis with the person with dementia, this is not done consistently (Bamford *et al.*, 2004). Another important factor that may not always be considered is the need to ensure that sharing a diagnosis is followed up by support (Keady *et al.*, 2004). Some social workers argue that

their skills in this area have been neglected and that they could play a fuller part in this process (Manthorpe and Iliffe, 2005b).

Treatments for dementia

A number of new drug treatments for dementia have been developed but the key question at the time of writing is whether they are cost effective (AD2000 Collaborative Group, 2004; Morris, 2005). There has also been considerable interest among practitioners in non-pharmacological treatments, such as aromatherapy (Thorgrimsen *et al.*, 2003; Holmes and Ballard, 2004), reminiscence (Woods *et al.*, 2005), reality orientation (Spector *et al.*, 2003) and memory training (Cahn-Weiner *et al.*, 2003; Clare *et al.*, 2003; Berger *et al.*, 2004). While these studies generally report positive benefits, the evidence is generally considered to be insufficient to support their widespread use (Douglas *et al.*, 2004) and further work is required (Woods, 2004).

Depression

Everyone experiences feelings of sadness and loneliness but depression can be distinguished from these everyday feelings because of its *intensity* ('I have never felt like this before'), *duration* (at least two weeks) and *lack of fluctuation* (absence of good days or good periods). Other symptoms associated with depression include loss of confidence or self esteem, feelings of helplessness, poor appetite and sleep patterns, feelings of hopelessness or worthlessness, feelings of guilt poor concentration, physical slowness or agitation, avoiding social contacts or going out, suicidal thoughts or behaviour (Manthorpe and Iliffe, 2005a, pp9-10).

How many older people have depression?

Depression is the commonest and the most reversible mental health problem in old age, affecting between 10-15 per cent of people aged 65 and over living at home in the United Kingdom (Anderson, 2001) but with less than two per cent experiencing it in its most severe form (Beekman *et al.*, 1999). The frequency of depression rises with age and is more common among people in their 80s and 90s than those in their 70s (Osborn *et al.*, 2003). There is conflicting evidence as to whether older women are at greater risk of depression than older men (Beekman et al., 1999; Katona and Shankar, 1999; Osborn et al., 2003).

Although only a minority of older people living in the community develop depression, there are at least twice as many people with depression among home care users (26-44 per cent) than we would expect to find in the older population as a whole (Banerjee and Macdonald, 1996; Banerjee *et al.*, 1996). Two studies (Harrison *et al.*, 1990; Field *et al.*, 2002) found high rates of depression among people living in sheltered accommodation, possibly because their move had been precipitated by bereavement and/or loneliness (Field *et al.*, 2002). However, another study suggested that living in sheltered housing might have a protective effect on mental health because of

the increased opportunities for social contact (Walker *et al.*, 1998). Depression is also extremely common among people living in long term care. In one study, forty per cent of people living in care homes had depression (Mann *et al.*, 2000) and in another just half of new admissions were depressed (Mozley et al., 2000).

What causes depression?

The causes of depression in old age are complex with demographic, social and biological factors all being implicated in its development (Katona and Shankar, 1999). Some people's depression can be traced to a single cause, while in others there are a number of reasons why it has occurred. Although there is thought to be a familial element to the most severe forms of depression (Sullivan *et al.*, 2000), older people experiencing depression for the first time in their lives are less likely to have a family history of depression (Katona and Shankar, 1999).

One of the most important risk factors for depression in old age is bereavement (Harwood, 2001), with men seeming to find it harder to adjust to the experience of widowhood than women (Bennett *et al.*, 2002). In addition to bereavement, other life events, such as the onset of serious illness, severe financial crisis and being a victim of theft are all associated with depression (Prince *et al.*, 1997b). Moving accommodation, severe illness in a loved one or separation from him or her have also been found to be associated with depression (Osborn et al., 2003). This demonstrates how moves to long term care must involve support not only for the person making the transition and but also for partners and close relatives and friends remaining at home.

Poor social support and loneliness make people more vulnerable to developing depression (Prince et al., 1997b; Osborn et al., 2003). Most older people in the UK have frequent contacts with members of their family, friends and neighbours, but between 9-15 per cent report that they regularly feel lonely with single never married and widowed people and people aged 75 and over reporting more loneliness than married older people or those in the 65-74 age group (Victor and Scharf, 2005). However, contrary to some people's preconceptions, loneliness is not restricted to people in the older age group and neither is there any evidence that older people today are more lonely than in the past (Victor *et al.*, 2002).

There is a strong relationship between depression and socio-economic status, with people on lower incomes experiencing poorer mental health (Prince et al., 1997b; Harrison *et al.*, 1999; Osborn et al., 2003).

Depression may also occur as a result of physical illness and disability (Prince *et al.*, 1997a; Osborn et al., 2003; Gottlieb *et al.*, 2004).

Why depression remains under-recognized

Both older people and professionals underestimate the significance of late life depression (Manthorpe and Iliffe, 2005a). Many older people do not see depression as an illness and so do not ask for help (Marwaha and Livingston, 2002). Recognition of depression in old age may be more difficult in that symptoms such as poor concentration or loss of interest in usual activities or hobbies can mimic dementia (Badger, 1998) but a US study found that training can help staff involved in day to day care to become better at identifying depression (McCurren *et al.*, 1999). Under recognition may also occur when professionals suspect that an older person is depressed but fail to take any further action, either because they feel uncomfortable about their ability to raise psychosocial issues with him or her (Iliffe *et al.*, 1994; Howe *et al.*, 2000) or when they think that 'nothing can be done' (Anderson, 2001).

Treatments for depression

Many older people with depression will benefit from antidepressants (Wilson *et al.*, 2001) or from antidepressants in conjunction with other non-pharmacological interventions (Baldwin and Wild, 2004). Bereavement counselling, life review and similar interventions may help (Cole and Dendukuri, 2004). The most effective interventions aimed at alleviating social isolation and loneliness among older people are those that have a focussed educational input or provide targeted support activities, are aimed at specific groups (for instance, people who have been widowed), are built around an existing service, and where older people have been consulted about the intervention beforehand (Cattan *et al.*, 2005). Advice from older people who have been bereaved suggests that keeping busy, taking part in social activities, helping others, social support and being able to talk about the deceased person to others all help in coming to terms with bereavement (Bennett et al., 2002).

The consequences of not offering support to people with depression are very serious. Without help, there is a greater risk that the depression will become chronic (Beekman *et al.*, 2002). Although there is some evidence of a fall in suicide rates among older people (Gunnell *et al.*, 2003), older people account for between 20-25 per cent of all completed suicides even though thy comprise only 15 per cent of the population (Baldwin, 2002). Men aged 75 and over are a group who are particularly at risk.

Anxiety

A community study of people aged 65 and over found that 15 per cent of the sample had an anxiety disorder, a similar prevalence to that of depression (Manela *et al.*, 1996). Anxiety may co-exist with depression (Beekman *et al.*, 2000) and dementia (Ballard *et al.*, 1996).

Alcohol and substance misuse

In the UK, older people consume less alcohol than younger people (Walker *et al.*, 2001) but changes in the age structure of the population and in societal attitudes to alcohol make it likely that the number of older people with alcohol problems will increase. However, comparatively little attention has been given to alcohol misuse in late life, despite its potentially severe social and health consequences (Johnson, 2000). Five per cent of older men and 2.5 per cent of older women admit to drinking above the recommended safe limits of 21 units for men and 14 units for women per week (Hajat *et al.*, 2004) but there is concern that alcohol misuse in older people is overlooked (Walker et al., 2001; Marshall *et al.*, 2003). There is even less information on the misuse of prescribed and unprescribed substances among older people. While it is generally agreed to be rare in this age group, as with alcohol, changing societal and cohort attitudes to the use of drugs may result in differences in the future (Derry, 2000).

Enduring mental health problems and intellectual disabilities

The number of older people who develop serious mental health problems in old age, such as psychoses, is comparatively small. However, with increasing longevity, the number of older people with long term mental health problems or intellectual disabilities is likely to increase (Ashaye *et al.*, 1997). Models of best practice indicate a need for regular assessments to ensure that changes in cognitive, behavioural and social functioning are identified (Hatzidimitriadou and Milne, 2005).

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4. ASSESSING OLDER PEOPLE WITH MENTAL HEALTH NEEDS: WHAT WE KNOW FROM RESEARCH

Summary

There has been little research focussing upon how older people themselves feel about being assessed. The limited research evidence available shows that professionals and service users may not share the same ideas about what constitutes a 'good' assessment. It is important that professionals take time to understand people's strengths, as well as their difficulties. The use of standardized measures in an assessment may help pick up issues that may otherwise have been overlooked. The most important factor of all is the development of good communication skills that will mean that assessors are able to establish their needs and preferences even of people with severe communication skills.

Older people's experiences of assessment

Until recently, comparatively little importance was attached to including the views of older people in the assessment process (Vernon *et al.*, 2000) and so it is perhaps unsurprising that so little research has been undertaken into how they feel about the experience of being assessed. Of this, only a minority has been undertaken with older people with mental health problems and we are often reliant upon messages from the wider older people's literature. Personal accounts by professionals who have themselves undergone the experience of being assessed also give a vivid indication of how even articulate people who are familiar with how social and health care systems operate can feel disempowered by the process (Genevay, 1997; Tinker, 1997; Avebury, 2004).

The most important point to remember is that assessment is not a neutral process (Keady and Bender, 1998) and so people being assessed are likely to feel some anxieties. The recognition that the assessor is looking for signs of cognitive impairment is felt to be especially stressful (Tinker, 1997), especially if the person is worried that an unsatisfactory score will result in them being viewed as unable to manage their lives independently (Moriarty and Webb, 1997, 2000). Carers may also find the process of negotiating with health and social care professionals difficult. A survey of carers of people with dementia revealed that while the majority of participants found attending a ward round a useful experience, a minority, especially those caring for spouses, found it stressful. They suggested that an improvement would be for them to have been provided with details about the composition and purpose of meetings beforehand (Bains and Vassilas, 1999).

In addition to any concerns about the purpose and process of assessments, many older people are aware that resource considerations may influence the outcome of an assessment. This may prevent them from expressing their preferences fully (Hardy *et al.*, 1999). This phenomenon has been described as self rationing (Hardy et al., 1999; Arksey, 2002).

Another way in which older people may feel constrained from participating in assessments fully stems from the manner in which practitioners undertake assessments. There is growing evidence that practitioners face conflicts between negotiating on behalf of service users and on behalf of the agency for which they work (Ellis *et al.*, 1999; Parry Jones and Soulsby, 2001; Postle, 2002). In these circumstances, the needs of service users are subsumed to those of the agency (Martin *et al.*, 1999). This seems to contribute to a situation in which older people's needs are defined by professionals and not by themselves (Chevannes, 2002).

Given the absence of a substantial body of research based upon older people's accounts of being assessed, even greater importance has to be placed upon studies where researchers have observed assessments taking place. Results from these suggest that many assessments do not give service users the opportunity to raise all the issues that concern them and receive answers to all their questions (Stanley, 1999; Richards, 2000).

Components of good assessment practice

Although there will always be subjective elements to how different professionals and service users define 'good' and 'bad' assessments, there are some consistent messages from research. The importance of establishing good working relationships is paramount; without a relationship there is little chance that service users will be empowered (Stevenson and Parsloe, 1993). It is also important to place a person 'within the context of his or her life world and to appreciate its worth to him or her' {Jenkins, 2001 #567, p96}. The way people relate to the prospect of contact with health and social care services is influenced by their own identity. Concerns about 'strangers in the house', giving up their independence, or concerns about service quality will all act as a barrier to service use (McKevitt *et al.*, 2005). If assessors do not appreciate these complexities, there is a danger that they will both underestimate the areas of difficulty that are important to older people themselves and underestimate older people's resourcefulness and strengths in dealing with them (Pound *et al.*, 1999; Tanner, 2003). This may result in offers of unwelcome or inappropriate help (Richards, 2000).

It is also important to acknowledge that the aspects of an assessment that service users value are not necessarily the same as those of agencies. A study of Asian carers showed that they valued 'friendliness' and continued contact with professionals (Hepworth, 2005).

Research shows that many carers do not link receiving an assessment with the subsequent provision of services (Seddon and Robinson, 2001; Hepworth, 2005). This may influence their perception of the usefulness of assessments and highlights how important it is for assessors to discuss the results of their assessment with service users and carers.

Using standardized measures

Standardized measures have standardized instructions for administration, use, scoring, and interpretation with standard printed forms and content, often with standardized statistical properties which have been validated on a large sample of a defined population (Scriven, 1991). The advantage of data collected this way is that it enables information to be aggregated and for the results to be compared across different settings and regions. Since the introduction of the Single Assessment Process (SAP) for older people as part of the National Service Framework for Older People (Department of Health, 2001), there has been greater interest in identifying suitable standardized measures for use in assessments. To a great extent, this reflects concerns about the huge variation in the assessment documentation used in social services departments prior to the Single Assessment Process and the lack of attention to ensuring its reliability and validity (Stewart *et al.*, 1999).

Some of the advantages in using standardized measures are that they:

- improve the recognition of problems when compared with professional judgement alone (O'Connor *et al.*, 1988; Iliffe *et al.*, 1994; Dorfman *et al.*, 1995; Eccles *et al.*, 1998);

- help identify when people are under reporting a problem (Blaxter, 1990; Clark *et al.*, 1998; Casten *et al.*, 2000; Turvey *et al.*, 2000).

- are often multidimensional (meaning that they measure several aspects of a person's life) thereby providing a comprehensive snapshot of a person's needs where clinical expertise is found in separate disciplines (Robinson *et al.*, 1986) or where different professionals assess in different ways (Worth, 2001).

Communication skills

Nevertheless, having a good assessment tool does not guarantee a good assessment:

> *No one shot assessment will provide a complete picture of a person; the real picture will be filled out only over time...Having an assessment tool with comprehensive and relevant content does not assure a good assessment. A good tool goes hand in hand with good interviewing skills...Practitioners must have the ability to build rapport, ask effective open-ended questions, introduce difficult content, ...while showing interest [in the person being assessed].*

> (Morrow-Howell, 1992, p404)

Good communication skills are seen as integral to assessments and the failure to communicate effectively may lead to serious consequences (Trevithick *et al.*, 2004). However, although there is a substantial literature on communication skills, the majority of it is based upon practice rather than research.

The use of 'down to earth' language and the avoidance of 'jargon' were valued in one study of carers. They also liked assessors who were easy to talk to and who were good listeners (Arksey *et al.*, 2000). As well as being conscious of their own language, assessors need to be aware that older people and carers may attach different meanings to the same words, as in the use of the phrase 'I'm managing' which older people may have used to indicate that 'I am managing with difficulty' but assessors may interpret as meaning that the person does not require any help (Barrett, 1993).

People with cognitive impairment may find it harder to understand what is said to them and to express what they want to say. Evidence from the growing number of studies looking at the experiences of people with dementia shows that it is not that people with dementia are too difficult to communicate with; rather that assessors need the right skills and preparation to communicate with them (Wilkinson *et al.*, 2003). These include the:

- importance of taking time to build up a relationship with the person with dementia

- need to try and identify underlying meanings to what is said

- use of prompts such as photographs

- use of indirect means of collecting information where the person with dementia takes the lead in conversations, rather than direct questioning (Barnett, 2000; Allan, 2001; Tibbs, 2001; Wilkinson, 2001).

There is also a small but growing literature in which people with dementia discuss this issue (Wilkinson, 2001; Sterin, 2002).

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5. CARERS' NEEDS: WHAT WE KNOW FROM RESEARCH

Summary

There is a substantial amount of research looking at the needs of carers and it shows that there are three key reasons why it is important to provide comprehensive support for carers.

- The impact of looking after another person, particularly when that person requires very substantial help, may have a negative effect on carers' lives.

- Practical help and interventions aimed at helping carers to cope with day to day situations that they find difficult make a positive difference to carers' lives.

- Individuals respond to taking on caring roles in different ways and the help that they need will vary accordingly.

Impact of caring

Caring affects people's lives in many ways. Although it is difficult to show that it leads directly to poor psychological health, there is strong evidence that some carers are in poorer psychological health than people of a similar age and gender without any caring responsibilities in the general population (Buck *et al.*, 1997; Hirst, 2003). Many carers are themselves older and so are likely to experience physical health problems of their own (Milne *et al.*, 2001). They frequently report that they feel social isolation and loneliness, either because they no longer have the time to meet up with family members and friends, or pursue hobbies or other interests or because their relationship with the person from whom they care has altered. This is important because people with poor social support tend to rate their quality of life as poor (Helgeson, 2003) and carers who do not have someone to confide in report higher levels of depression (Waite *et al.*, 2004). Carers are also likely to be financially disadvantaged. Extra expenditure may be required to pay for equipment, services, heating and clothing. In addition, carers may give up paid employment, forgo promotion prospects or retire early. While women are still more likely to be affected more severely than men, particularly in terms of being able to build up savings and a pension in retirement (Ginn and Arber, 1996), this is an issue for both men and women (Carmichael and Charles, 2003). Carers find some aspects of caring more difficult to cope with than others. In particular, feeling unable to deal with behavioural changes such as wandering, night time disturbance or aggression are rated as especially hard to deal with (Levin *et al.*, 1989; O'Connor *et al.*, 1990; Draper *et al.*, 1995; Clark *et al.*, 2003). Being unable to leave the person alone has also been associated with poorer psychological health (Resource Implications Study of the Medical Research Council Cognitive Function and Ageing Study (RIS MRC CFAS), 1999). Caring for someone with dementia is felt to be more difficult than other types of caring because of the greater intensity of caring

required and because carers report that their lives have been affected in multiple ways (Parker and Lawton, 1994; Ory *et al.*, 1999; Bruce *et al.*, 2005).

Not everyone agrees with the way that research has addressed the complexities and reciprocities of the relationships between carers and those for whom they provide support, particularly in the emphasis upon the problems faced by carers (Morris, 1997; Nolan *et al.*, 2001; Forbat, 2005). Despite this, not every carer will need help and where research on caring has proved to be especially useful is in identifying carers at especial risk of experiencing difficulty. These tend to be:

- Spouse carers (Murray *et al.*, 1997; Leinonen *et al.*, 2001), especially those lacking social support (Livingston *et al.*, 1996) and those who have recently ceased to care (Buck et al., 1997).

- Carers who live with the person for whom they care and those providing especially intensive caring (Parker and Lawton, 1994; Hirst, 2003).

- Carers caring for someone with a mental health problem (Ory et al., 1999).

- Carers who have had a poor relationship with the person for whom they care (Levin et al., 1989; Levin *et al.*, 1994; Braithwaite, 2000).

- Carers who do not have a person in whom they can confide (Waite et al., 2004).

The support carers need

Assessment

Assessment of carers needs is essential in order to identify the help that carers need yet many reports from carers describe difficulties in accessing services and lack of attention to their needs on the part of health and social care professionals (Moriarty and Webb, 2000; Seddon and Robinson, 2001; Bruce *et al.*, 2002). In addition, many carers are reluctant to ask for help and may only approach services once they are experiencing difficulties. This makes it less likely that they will be offered help at a stage when preventative services will make a difference to their lives (Jarvis and Worth, 2005).

Carers generally feel that assessments have been worthwhile when they have resulted in:

- access to information;

- a new or additional service;

- an opportunity to discuss their position in an objective way with an experienced professional (Nankervis *et al.*, 1997; Moriarty and Webb, 2000; Seddon and Robinson, 2001).

Although assessors will not always be able to provide carers with all the help they would necessarily like, the way that carers are treated is an important element of satisfaction with an assessment. Carers feel it is important that they:

- feel included in decision making and that their expertise as carers has been acknowledged;

- know who to contact if needed;

- think that the service was responsive to their needs (Cox, 1996; Nolan et al., 2001; Walker and Dewar, 2001; Nolan *et al.*, 2003).

Where carers are looking after someone with a long term condition or one that deteriorates, they may find it increasingly difficult to provide care as time goes on. This means that assessments should not be a one off process and that reviews should take place regularly (Levin et al., 1989; Levin et al., 1994; Moriarty and Webb, 2000). There is some support for the model of specialist ongoing support, rather than carrying out an assessment (Woods *et al.*, 2003).

Services that support carers

Although services provided for the person for whom they care, such as home care, or wider welfare policies, such as family friendly employment policies, will benefit carers, the two main types of service aimed at supporting carers are services designed to give carers a break from caring, generally called respite services, and interventions aimed at helping carers manage their caring responsibilities, such as carer education.

Respite services include the broad range of services, including overnight respite, day care, and home-based respite but many carers are offered only a single service or none at all. However, a single service is unlikely to meet carers' ongoing needs fully and a wide range of services needs to be provided in order to meet the diverse preferences of carers and those for whom they care. Carers will be reluctant to use services if they are seen as having a detrimental effect on the person for whom they care. Inconsistent charging policies are another barrier to their use (Arksey *et al.*, 2004). The way in which we measure the success of respite services has changed to some extent. We are now more likely to evaluate them on the basis of whether they have made a positive difference to carers' lives, rather than seeing whether they delay admissions to long term care or lead to improvements in carers' psychological health. This underlies the importance of defining outcomes in consultation with carers themselves (Nicholas, 2003).

With a few exceptions, there is a shortage of systematic UK based evaluations looking at the impact of educational and training on carers. Carers who participated in a cognitive behavioural therapy (CBT) programme found that it helped them mange their caring role better (Marriott *et al.*, 2000). In the US, a psycho-educational group helped improve carers' reactions to disruptive

behaviors (Ostwald *et al.*, 1999) but a similar Australian study (Brodaty *et al.*, 1994) and a meta-analysis of published studies concluded that interventions of this sort needed to be tailored more to carers' individual needs if they were to make a difference (Brodaty *et al.*, 2003). Evidence from the US and Switzerland suggests that carers from minority ethnic groups (Monaghan *et al.*, 1992) and carers from routine and semi routine socio-economic backgrounds (Wettstein *et al.*, 2004) are under-represented in conventional interventions of this type. This highlights the importance of ensuring that issues of equity are addressed. In addition, some carers, particularly spouses, may be reluctant to try services (Robinson et al., 2005), hence the need for skill in discussing the advantages and disadvantages of different types of support and in arranging alternatives when existing forms of support are unsuitable. More work is needed on identifying different cultural preferences for different types of service, as the US literature suggests that this may be the case (Pinquart and Sorensen, 2005).

Legal position

The existence of legislative structures to support carers do not, in themselves, guarantee that carers will receive all the help that they need (Montgomery and Holzhausen, 2003-2004). In particular, carers may be unaware of the existence of legislation aimed at supporting them (Moriarty and Webb, 2000; Seddon and Robinson, 2001). Furthermore, the way in which national and local public bodies and front-line practitioners set priorities as a result of legislative changes may mean that the full potential of measures to support carers may not be realised and that rationing of services continues to take place (Arksey, 2002).

Conflicts of interest

It has long been recognised that while there may be some overlap between the perspectives of carers, those for whom they care and professionals, there will also be differences (Higginson and McCarthy, 1993). The perspectives of carers and those for whom they care are likely to resemble eachother in terms of identifying what are the needs of the person cared for but differ in terms of how they perceive the difficulties in meeting these needs (Lyons *et al.*, 2002). Little is known about how professionals deal in practice with situations where the service user and carer's needs and preferences conflict, although there is some evidence that carers' wishes are more likely to carry the day because of the potential threat that they will withdraw their services (Twigg and Atkin, 1994). This is especially apparent in terms of admissions long term care where carers' unwillingness to continue caring often plays an important part in determining whether the person for whom they care remains at home (Levin et al., 1989; Levin et al., 1994; McKee *et al.*, 1999; Gaugler *et al.*, 2003).

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6: THE NEEDS OF OLDER PEOPLE FROM BLACK AND MINORITY ETHNIC COMMUNITIES: WHAT WE KNOW FROM RESEARCH

Summary

Until recently, very little was understood about the needs of older people from Black and minority ethnic groups, partly because it was felt that their numbers were comparatively small and partly because of the stereotyped assumption that older people from Black and minority ethnic groups would have family members to look after them if they needed assistance (Blakemore and Boneham, 1994; Ahmad and Atkin, 1996; Butt and Mirza, 1996). With the ageing of Britain's minority ethnic population and greater understanding about their patterns of family and support, there has been more emphasis on remedying this situation. Nevertheless, there is still a shortage of studies in this field. What there is, shows clearly that there are lower levels of awareness about problems such as dementia and depression in these communities and that they continue to experience problems in accessing help from services.

Mental health and Black and minority ethnic groups

The mental health needs of older people from Black and minority ethnic groups have been particularly neglected, especially in comparison with the attention given to severe and enduring mental health problems among Black Caribbean adults of working age. As the proportion of people aged 65 and over among Britain's minority ethnic population increases, especially among Black Caribbeans and Asian Indians (Office for National Statistics, 2002), it has become increasingly important to ensure that more account is taken of their needs when planning and providing services.

Estimating whether some ethnic groups are more likely to experience different mental health problems than others is challenging because of the different ways in which ethnicity has been defined (Bhopal, 2004). It is also important to take account of other features that are known to influence people's mental health such as their income, housing, age and gender (Modood *et al.*, 1997; Brugha *et al.*, 2004). The impact of migration may also have had an impact on their mental health (Bhugra and Jones, 2001). It is also important to take account of the way that samples have been selected and whether the assessment methods used are cross culturally valid, meaning that they are suitable for use with a different group from those for which they were originally devised.

Studies tend to present a contradictory picture in terms of whether there are ethnic differences in the proportion of older men and women with anxiety and/or depression, the commonest mental disorders. Local studies have found higher rates of depression among older Cypriot (Livingston *et al.*, 2001) and Bangladeshi people (Silveira and Ebrahim, 1998) in London and Black African men in Liverpool (McCracken *et al.*, 1997). White people may be more likely to experience anxiety (Shaw *et al.*, 1999; Bhui *et al.*, 2004) but

these studies were not restricted to older people. National studies (Nazroo, 1997; Weich *et al.*, 2004) suggest that there are modest but important ethnic differences in the proportion of men and women with depression and/or anxiety. Importantly, age and gender also need be considered. While Asian Pakistani and Asian Indian women aged 55-74 are more likely than White women of a similar age to experience depression and/or anxiety, it is younger Irish and Pakistani men who have higher rates of depression and/or anxiety (Weich et al., 2004).

Even greater challenges arise when looking at the prevalence of dementia across ethnic groups because the degree of proficiency in the language used in test and levels of educational attainment may all influence people's results. Nonetheless, some differences have been found in the prevalence of dementia among different ethnic groups. In particular, higher rates of dementia have been found among Black Caribbeans (Richards *et al.*, 1999; Livingston et al., 2001). It has been suggested that this is related to higher rates of hypertension (high blood pressure). A small scale study in Bradford also suggested that Asian people were morel likely to have vascular dementia than Alzheimer's disease (Bhatnagar and Frank, 1997). In the United States, there have been a greater number of studies examining ethnicity and dementia, although the variation in ethnic groups in comparison with the UK and their different histories may limit the usefulness of applying results from US research to the UK. A similar picture emerges, suggesting that vascular dementia is more common among African Americans but that Lewy Body dementia is less frequent (Froehlich *et al.*, 2001; Fitzpatrick *et al.*, 2004).

Awareness of mental health problems in Black and minority ethnic communities

Recognition of the symptoms consistent with mental health problems within families is crucial if people are to seek advice and help from health and social services. It has been suggested that recognition of dementia is lower among South Asian and Black Caribbean people than among the population as a whole (Adamson, 2001; Bowes and Wilkinson, 2003). It is also possible that levels of stigma about mental health are higher in some communities than others (Ng, 1997; Marwaha and Livingston, 2002; Bowes and Wilkinson, 2003).

Particular needs

There is evidence that lack of awareness about what help is available makes it less likely that people from minority ethnic groups will receive all the help that they need (Ahmad and Atkin, 1996). Although a concern that services will not be culturally sensitive is one reason why people from minority ethnic groups do not use services (Blakemore and Boneham, 1994), there is a concern that health and social care professionals may *assume* that Black and minority ethnic people will reject a particular service and so fail to offer it at all (McKevitt *et al.*, In press). This is why culturally aware staff are needed to

assess older people with mental health problems, particularly dementia (Rait *et al.*, 1999; Daker-White *et al.*, 2002).

Comparatively little UK research has looked at the position of carers from Black and minority ethnic groups. It suggests that while they share many similarities with their white counterparts, they face additional problems in terms of finding it harder to get information and access suitable services (Bowes and Wilkinson, 2003; Katbamna *et al.*, 2004; Adamson and Donovan, 2005). Younger carers and those who feel that they do not receive enough support from other family members may find it especially hard (Dilworth-Anderson *et al.*, 2002; Bowes and Wilkinson, 2003; Katbamna et al., 2004; Adamson and Donovan, 2005)

Service responses required

There are few published accounts of ways in which services have improved their responses to older people from Black and minority ethnic groups and their carers, although those that do emphasise the need to work with local communities and to develop a skilled workforce that matches the population it serves (Moriarty, 2002; Bowes and Wilkinson, 2003). This highlights the importance of developing culturally sensitive services (Katbamna *et al.*, 1998; Moriarty, 2002; Bowes and Wilkinson, 2003). However, a review of services for people with dementia from marginalized groups concluded that there was little consensus about whether services should be provided specifically for different ethnic groups, reflecting a lack of evidence concerning the efficacy of different models of service provision (Daker-White et al., 2002). Carers' groups for specific minority ethnic groups may also help. This is not only because of language issues but because some people may find it easier to share experiences with people of a similar background to themselves (Ismail and MacKenzie, 2003). At the same time, US research highlights the importance of culturally sensitive services but also emphasises service preferences are shaped by many experiences such as lifestyle or other attitudinal factors (Sciegaj *et al.*, 2004). This shows the complexities required in developing services that are responsive to the needs of the whole community.

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7: MEETING NEEDS: WHAT WE KNOW FROM RESEARCH

Summary

There is no universally agreed definition of need and older people with mental health problems may have differing views from professionals on the extent to which an assessment and any subsequent offers of help are actually meeting their needs. The models of care management that work best for older people with mental health problems tend to involve continued contact, as opposed to a one-off assessment, but most older people with mental health problems do not experience this type of support. Home care and day care can be effective in supporting people with dementia but there has been a failure to invest in systematic evaluations of existing and new forms of community services. Housing, housing support and assistive technologies are playing an increasing role in supporting people living at home and this is reflected in the increasing policy interest in the role of preventive services. Although high proportions of people with depression are found among users of home care, day care and long terms care services, little attention has been paid to finding out what help would benefit them best. There is an important role for professionals in helping older people with mental health problems reach difficult decisions such as agreeing on an acceptable level of risk or deciding to move into long term care but there is growing evidence that organizational pressures in terms of budgetary and bureaucratic constraints are limiting their ability to meet the multiple and complex needs of this group of service users and their carers.

What do we mean by need?

Although 'need' is one of the most widely used terms in social care, there is little consensus at a theoretical, policy or practice level on what it means or how it might be measured (Godfrey and Callaghan, 2001). On the whole, organizational and professional definitions of need have predominated over those made by service user and carers (Cordingley *et al.*, 2001; Godfrey and Callaghan, 2001). This is to some extent reflected in research looking at the effectiveness of community and long term care services where, until recently, success was often described in terms of the extent to which policy or organizational objectives were met without reporting on service user and care experiences.

Practitioners have always been faced with the challenges that arise from trying to meet the needs of individuals whom they have assessed and the pressure to contain the resources of the organization for which they work. This has sometimes led them to be unwilling to discuss needs that cannot be met with service users and carers in case they raise false expectations (Ellis, 1993; Caldock, 1994). A growing number of studies are now suggesting that this longstanding tension has worsened and that practitioners are finding it increasingly difficult to negotiate between organizational constraints and meeting service users' needs. As a consequence, there has been greater emphasis upon rationing services than on meeting needs (Ellis *et al.*, 1999;

Rummery and Glendinning, 1999; Parry Jones and Soulsby, 2001; Martin *et al.*, 2004).

Challenges in identifying how effective services are at meeting needs

One of the key reasons for undertaking an assessment is to help decide the type and level of support that will be offered to the person who has been assessed. However, evaluating the effectiveness of community and long term care services remains one of the most difficult research undertakings and our evidence about which ones are best able to meet the needs of older people with mental health problems remains comparatively limited.

Why should this be the case? Older people with mental health problems generally have quite complex health and social care needs and usually require more than one service. Unfortunately, evaluations of combinations, or packages, of services remain rare and it is more common to find accounts of a single service, such as home care or day care. Furthermore, many of these studies have been undertaken with undifferentiated groups of older people such as 'frail elderly' and there are far fewer accounts focussing upon the needs of older people with mental health problems. In addition, it generally takes time for the effects of a new or changed package of care to become clear. This requires studies that have a follow-up design yet cross-sectional (one point in time) accounts still predominate. While lessons can be learnt from longitudinal research undertaken outside the UK, there are considerable problems in applying these models of service delivery to the UK. We have also changed the way that we evaluate the outcomes of services (Qureshi, 1999, 2003). Most of the existing evaluative studies were undertaken some years ago when the extent to which community services could prevent older people with mental health problems from being admitted to long term care was seen as the primary indicator of service effectiveness. While information on when and where people are admitted for long term care is essential for undertaking an economic evaluation and it remains a vital pointer as to whether people's service preferences are being met, there is now greater acknowledgement that other aspects, such as improvements to quality of life, may be equally important. These earlier studies either did not collect this information or did not report on it. Unfortunately, they have yet to be replicated to take account of changing ideas about appropriate outcome measures and more recent service developments, such as extra care housing and assistive technology. They remain, however, our best source of evidence on service effectiveness.

What older people with mental health problems want from services

Older people with mental health problems have similar aspirations and expectations to other older service users. For example, older people with dementia value services that:

- treat them as an individual;

- give them access to social contact and company;

- give them a sense of social integration and access to meaningful activity and stimulation;

- maximize their sense of autonomy;

- make them feel safe and secure; and

- make them feel valued and respected.

(Bamford and Bruce, 2000)

In terms of their relationships with care staff, personal qualities such as being warm and friendly may be more important than efficiency (Moriarty and Webb, 2000).

Effective services from the perspective of older people are those which: directly maintain, or remove barriers to achieving, quality of life (keeping clean and comfortable, living in a clean and orderly environment, being safe, having access to social contact and company, being able to keep active and alert, and having control over one's life) and which do so in a way which ensures that people are treated as fellow citizens with respect for their individual priorities and circumstances (Qureshi and Henwood, 2000, p23).

Does early intervention make a difference?

Although early intervention is generally agreed to be beneficial in terms of maximizing the potential benefits of access to treatment and support (Department of Health, 2001; Office of the Deputy Prime Minister, 2005), there is concern that older people with mental health problems and their carers do not have access to the right sort of information and help early enough (Audit Commission, 2000b, 2000a). These delays may occur either because people are unaware that they may have a problem or are unwilling or afraid to ask for help (Corner and Bond, 2004; Bond *et al.*, 2005; Rimmer *et al.*, 2005) or because health and social care professionals do not identify what is wrong or are unduly pessimistic about what might help (Iliffe, 1997; Audit Commission, 2000b, 2000a; Anderson, 2001). (See Section 3). Outside the UK, early intervention programmes have been welcomed as reducing the numbers of frail older people being admitted to long term care (Lledo *et al.*, 1997; Callaly *et al.*, 2004; Friedman *et al.*, 2005). However, a UK study of an early intervention team for people with dementia pointed out that such teams might actually *increase* the number of admissions because of the identification of problems that might otherwise have remained unrecognized (O'Connor *et al.*, 1991). It is also important to recognize that increasing the numbers of people seeking help at an early stage requires a multi-pronged approach. Experience from the Australian *beyondblue* campaign to raise public awareness about depression suggests that positive benefits can be achieved but that they take time to occur and that there are limits to what can be achieved even by a well-resourced and well designed programme

(Pirkis *et al.*, 2005). This means that proactive responses on the part of service providers, such as outreach work, will continue to be required.

What is the right balance of care?

In recent years, discussions about the sort of help that older people are offered have been dominated by debates about the *balance of care*, the term used to describe the relative priority that should be given to services supporting people living in the community and long term care services in homes or hospital (Hughes and Challis, 2004).

In the UK and in parallel developments in Europe, Australasia and North America, government policies relating to the care of older people have sought to substitute more expensive forms of care, such as hospitals, to less expensive forms of care, such as home care. These policies have been based on the assumption that:

- There are some individuals who require lesser levels of care than those provided in the setting in which they are currently located.

- Improved co-ordination of care will reduce the possibility of people being mistakenly offered care that is inconsistent with their needs.

(Challis, 2002)

Although these policies were primarily aimed at targeting resources on people who were already vulnerable, government policy has recently shown greater interest in preventive services, geared towards promoting independence and reducing the possibility of crises occurring at a later date (Office of the Deputy Prime Minister, 2005).

Do preventive services make a difference?

Interest in the value of preventive services for older people is comparatively recent (Iliffe and Drennan, In press). The concept of prevention has also been used quite loosely (for instance, preventive home visits, follow up care, health promotion and direct care provided in the home) and comparatively few studies have taken a rehabilitative or preventive approach in terms of how older people and their carers can be enabled to take a more proactive role in dealing with their support needs (Hallberg and Kristensson, 2004).

The benefits of comprehensive assessments

The majority of research into preventive services has looked at the effects of comprehensive multidimensional assessments that span people's medical, functional, social, psychological, and environmental needs upon frail older people. Reviews of the international literature (Stuck *et al.*, 2002; Elkan *et al.*, 2003) have suggested that they generally lead to reductions in rates of mortality and admission to long term care and improvements in functional status (a person's ability to lead an everyday life) but not all studies have

produced consistent results across each of these measures (Fletcher *et al.*, 2004; Rubenstein, 2004). However, a major study undertaken in the UK suggested that different types of multidimensional assessment (universal versus targetted, hospital outpatient geriatric team (authors' description) versus primary care) produce only minor differences in outcome. The main benefit occurred in terms of improved social interaction where those receiving care from a specialist geriatric team had better social interaction than those receiving standard primary care (Fletcher et al., 2004). Commenting on these findings, Stuck and colleagues (2004) suggest that the study re-confirms the importance of follow up visits, as opposed to one-off assessments (Alessi *et al.*, 1997) and the need to target different sorts of preventive intervention on different service users (Bula *et al.*, 1999).

Low level preventive services

Another way in which research has sought to look at preventive services has been to examine the impact of 'low level' services such as such as help with housework and home maintenance. These studies (Clark *et al.*, 1998; Lewis *et al.*, 1999) are small in number and have been undertaken with generic groups of older people, not specifically among those with mental health problems. They show that service users rate these services highly and feel that they have given them an improved quality of life. However, because these studies have been small scale and qualitative, there is an unresolved debate between those who favour these forms of support and those who argue that the evidence does not provide sufficient grounds for the levels of public investment that would be required to sustain them.

Specialist services for older people with mental health problems

Research on different models of care management has highlighted that the most effective case management interventions are those targeted on a highly specific client group (Davies *et al.*, 1990). An evaluation of an intensive care management scheme for people with dementia in a community mental health team (CMHT) compared with people receiving the 'standard' service from a similar team showed that there were fewer admissions to long term care, increases in social and physical functioning and reductions in risk and in carer stress among those receiving the care management service (Challis *et al.*, 2002) However, despite this evidence, the number of local authorities with an intensive care management service for older people remains very low (Challis *et al.*, 2001).

Outside of care management approaches, an evaluation of the carer-focussed Admiral Nurse service showed that it did not differ from conventional services in terms of reducing carer stress or admissions to long term care. However, the results do lend some support for a dementia-specialist service which engages with carers and provides continued involvement for as long as is required, rather than simply carrying out an assessment and referring the person back to social services or primary care (Woods *et al.*, 2003). However, such approaches remain comparatively unusual and most care

managers spend very little time on monitoring or review or in providing counselling or support (Weinberg *et al.*, 2003).

Another area in which specialist assessments may assist in the identification of unidentified needs is in the provision of specialist assessments for those at risk of entry to long term care. A comparison of those receiving a specialist assessment in conjunction with the usual care management assessment found that the assessments revealed areas of need of which care managers had been unaware, particularly in terms of cognitive impairment. Older people who had received the specialist assessments deteriorated less and their carers experienced less stress than those receiving the standard care management service (Challis *et al.*, 2004).

Results from a trial in which depressed older people were randomly allocated to a follow up assessment by a member of a community mental health team or to routine general practitioner care suggested that these assessments were not effective in improving their levels of depression (Arthur *et al.*, 2002). As with preventive home services, what may be key is what happens *after* the assessment. In this study, ongoing support from the CMHT was offered at the discretion of the GP and there was a suggestion that there was a failure to meet raised expectations among the intervention group. By contrast, older people with depression who received support from an old age psychiatry service had much better recovery rates from depression than those who were supported by their general practitioner alone (Banerjee *et al.*, 1996).

Other community and long term care services

Community care services

Given the emphasis on the need for community services to support older people with mental health problems and their families (Zarit *et al.*, 1999), there are surprisingly few empirical studies on this topic. Although services such as day care and home care contain comparatively high proportions of older people with mental health problems (Livingston *et al.*, 1997; Moriarty, 1999), surveys have shown that there are high levels of unmet need (Philp *et al.*, 1995; Ely *et al.*, 1997). Unfortunately, there has been a shortage of studies of home care (Godfrey *et al.*, 2000) and day care (Moriarty, 2001) that have been undertaken since the community care changes and so it is difficult to identify the extent to which this problem continues.

Another limitation of existing research is that there is much greater emphasis on the effects of services upon carers (see Section 5) than upon older people. One study undertaken in three parts of the UK found that receiving home care and/or day care reduces the rate at which people with dementia are admitted to long care (Andrew *et al.*, 2000). Furthermore, the people using these services generally spoke warmly about them (Moriarty and Webb, 2000). The Audit Commission analysed the characteristics of over 500 older people receiving care from community mental health service professionals in care services and suggested that there was no single factor that made it

possible to support more dependent people in the community, but that the availability of good quality care, such as specialist home care, day provision with extended hours, respite care and sitting services in the person's home, all contributed. However, specialist home care schemes remain comparatively uncommon, although descriptive accounts suggest that they offer more advantages to people with dementia (Chilvers, 2003).

Several studies undertaken outside the UK have suggested that day care helps to reduce the frequency with which people with dementia experience problem behaviours (Kilstoff and Chenoweth, 1998; Gaugler *et al.*, 2003; Dröes *et al.*, 2004; Woodhead *et al.*, 2005). A Dutch study found that where day care is enhanced by attending a Meeting Centres Support Programme in which people with dementia and their carers have access to advice, social activities, groups and one-to one consultation with a professional, then this is more effective than day care alone (Dröes et al., 2004).

It is increasingly recognized that social and leisure activities for older people with mental health problems can be organized in such a way that they can be accompanied by their carers (Murphy and Sharp, 2000; Miesen and Jones, 2004) and can be undertaken in normal everyday settings, rather than specialist centres (Mitchell, 2005). However, this is an example where research lags behind practice and comprehensive evaluations are lacking.

Currently, there are very few older people with mental health problems using direct payments (Department of Health, 2005) but early results from an Italian study suggest that a combined programme of financial support and support from a specialist service have benefits for people with dementia and their carers (Fabris *et al.*, 2004). Experience from across Europe shows that older people as a whole can benefit from the increased choice that cash payments in lieu of care can provide but that this only works if alternative sources of help exist and if older people have access to advice and information about how to use them (Glendinning *et al.*, 2004).

Housing and housing adaptations

The majority of older people wish to remain in their own homes (Allen *et al.*, 1992; Boaz *et al.*, 1999; Henwood and Waddington, 1999) and housing now plays an increasingly important role in the provision of health and social care to older people. Initiatives aimed at enabling people to continue to live at home broadly consist of:

- help with improving housing quality, for example, help to carry out necessary repairs;

- adaptations, such as handrails or alterations to bathrooms and alarm systems, such as sensors to indicate that a person has left the room;

- additional support in the form of neighbourhood wardens, befriending schemes, sheltered and extra care housing.

Help with improving housing quality

Builders are increasingly being encouraged to construct new homes to the lifetime homes standard which means that they have been designed to take account of people's changing needs by providing, for example, easily reachable switches and sockets and lavatories at entry level (Carroll *et al.*, 1999). Although technically older stock can be adapted to meet lifetime homes standard, it is generally associated with new buildings. The majority of older people do not live in new homes and it is necessary to create home environments from the existing housing stock that are able to facilitate independent living. This involves tackling physical design features, the provision of assistive technology and the establishment of safe and secure environments that provide an acceptable level of risk for individuals and their carers (Barlow and Venables, 2004).

Help with repairs

In 2002, the government introduced a new definition for a 'decent home'. To be decent, a home must meet the current statutory minimum standard for housing; be in a reasonable state of repair; have reasonably modern facilities and services; and provide a reasonable degree of thermal comfort (Department of Environment Transport Regions, 2002). Although the majority of older people live in decent homes, the English House Conditions Survey shows that in 2001 there were 2.4 million households containing at least one person aged 60 and over living in a home that did not meet these standards. While it is not known how many of these have mental health problems, there are strong links between housing quality and mental health (Blackman and Harvey, 2001) and older people living in poor quality accommodation are at greater risk of experiencing depression (Stewart *et al.*, 2002). We do not know how much older people themselves spend on home improvements and repairs (Robinson and Banks, 2005) and the effects of changes in accommodation quality on older people's mental health is an under researched area. However, we do know that people with dementia who are unable to fund their own home improvements may find it more difficult to access support from home improvement agencies (HIAs). These are not-for-profit organizations helping help homeowners and private sector tenants who are older, disabled or on low income to repair, improve, maintain or adapt their homes. Staff working in HIAs need information and training to assist them in developing skills in working with people with dementia, especially in terms of understanding the nature of dementia, legal and financial issues and also in becoming familiar with the range of specialist assistive technologies that are increasingly available (McClatchey *et al.*, 2001; Means *et al.*, 2002).

Assistive technologies

The phrase assistive technologies is used to 'describe devices or systems allowing an individual to perform a task that they would otherwise be unable to do, or increasing the ease and safety with which the task can be

performed' (Cowan and Turner-Smith, 1999, p325). It is rapidly becoming preferred to alternatives such as aids and appliances, partly because it better reflects the range of technological advances that have taken place in recent years and partly because it gives a greater sense of how independence can be enhanced (Audit Commission, 2004).

Many of the assistive technologies used most often with older people with mental health problems are aimed at enhancing the orientation of people with dementia (such as reminder systems) or at improving their safety (such as monitors for cooker or water usage). These devices may also provide additional reassurance for carers (Baruch *et al.*, 2004; Kinney *et al.*, 2004). A major project undertaken across six European Union countries (including England and Ireland) found that they can be used by a considerable proportion of the participants and that they are useful in supporting their everyday activities. However, the extent to which they work as intended and the attitude of the person with dementia and his or her carer are crucial in determining whether or not they are perceived as being successful (Gilliard and Hagen, 2004). This mirrors research undertaken with older people (Lansley *et al.*, 2004; McCreadie and Tinker, 2005) and people with disabilities (Heywood, 2001) which highlights that assistive technologies work best when they are in accordance with service user preferences and when careful consideration has been taken of the environment in which they are being used or installed.

Additional support

Slightly higher rates of people with dementia and depression are found among people living in sheltered housing than in the general population (Walker *et al.*, 1998; Field *et al.*, 2002) but traditional sheltered accommodation may not always provide the amount of support that will enable them to continue living there if their difficulties worsen. This is why there has been considerable interest in the role of extra care housing in which additional services such as home care can be provided in to people living in self-contained units (Reynold, 2005). We will know more about the capacity of extra care housing to support people with dementia once the Housing 21/Dementia Voice longitudinal study of extra care housing for people with dementia has been published.

In contrast to Sweden where group living for people with dementia is widespread (Annerstedt, 1997; Keady and Lundh, 1997), the model adopted by the Dementia Care Partnership in Newcastle whereby people with dementia are placed in ordinary houses with support from paid care workers remains comparatively unusual (Svanberg *et al.*, 1998). Furthermore, older people with mental health problems comprise a very small proportion of those receiving funds from the *Supporting People* programme (Robinson and Banks, 2005) and so many older people with mental health problems have little direct experience of this type of support.

Long term care

Older people with mental health problems are at greater risk of entry to long term care. Although only five per cent of people aged 65 and over in the UK live in long term care (Royal Commission on Long Term Care, 1999), between two thirds (Bowman *et al.*, 2004) and three quarters (Mann *et al.*, 2000; Macdonald *et al.*, 2002) of them are cognitively impaired. As many as 40 per cent have depression (Mann et al., 2000), meaning that there is a substantial group of people living in long term care with both dementia and depression (Mann et al., 2000; Mozley *et al.*, 2000). Despite this, it does not always seem to be routine practice to ensure that care home staff have been informed about the results of any investigations into the mental state of their newly admitted residents and some of them appear not to have undergone any formal evaluation of their psychiatric state at all (Challis *et al.*, 2000; Mozley et al., 2000).

Social and health care practitioners have enormous potential to influence whether or not a move into long term care is seen as positive choice (Davies and Nolan, 2003). In reality, even though moving into a care home is a major life-changing decision, it is often taken when people have very little information, when they are under pressure to make a quick decision and when they are feeling unwell (Office of Fair Trading, 2005). Although many older people would prefer not to move to long term care, it is important to recognize that those who have made the move can identify advantages with their new home, including the safe environment, the care they receive and the company of others (Boaz et al., 1999; Hayden *et al.*, 1999). This process of adjustment also emerged in interviews undertaken with people with dementia who had moved into long term care (Moriarty and Webb, 2000).

Risk

A common precipitant of placement into long-term care is the recognition by an older person, his or her family members, and social and health care professionals that an individual older person is in a situation that places them at risk. There is comparatively little research looking at how professionals assess risk for people with dementia (Gilmour *et al.*, 2003) and research on older people with other mental health problems is generally restricted to the medical literature on identifying people at risk of attempting suicide.

The way in which of professionals perceive risk will influence their perceptions of a person's needs. This, in turn, will influence their decisions about a person's need for care. For example, professionals tend to assess the risks for people with dementia in terms of their physical safety. This means that they may concentrate upon meeting physical needs. People with dementia and their families may be more concerned about the risks that dementia poses to their self identity and social relationships. Thus, a person with dementia may feel that being able to leave the house unaccompanied produces benefits in terms of maintaining their sense of self identity which

outweigh the risks of having an accident or becoming lost (Clarke and Heyman, 1998; Clarke, 2000).

In taking greater account of the expertise of service users and carers in defining the levels of risk that are acceptable to them, professionals are also subject to organizational pressures to provide evidence of auditable expertise as a way of avoiding litigation and accusations of failure (Horlick-Jones, 2004). Two ways of minimizing harm that may occur to a person identified as being at risk have been put forward. The first is an in-depth knowledge of a person's biography that will enable professionals to place the risk in context (Clarke, 2000; Gilmour *et al.*, 2003). The second is the importance of trust between professionals, older people and their families (Gilmour et al., 2003; Huby *et al.*, 2004).

Refusing services

One of the areas of unmet need about which we know least is why people refuse services (Cordingley et al., 2001). Although refusing a service is a way of exercising choice, it is also important to consider whether the decision would have been different had another sort of help been available or if more information had been given. Robinson and colleagues (2005) adapted Anderson and Newman's model (1973) for use with people with dementia and their carers. Barriers to service use were categorized as *individual*, such as individual feelings of guilt, *societal*, such as not wanting to differ from a 'norm' of family care, and *institutional*, relating to questions of resources and/or the nature of the organization. While the community care changes have seen greater choice in terms of a greater number of service providers, the actual types of services available has expanded less (Hardy *et al.*, 1999). These barriers mean that skill is required both in developing new forms of service and in helping people to reach decisions about service utilization. However, this investment is worthwhile; those who initially refuse a service often go on to accept it later and are pleased that they changed their minds (Baldock and Hadlow, 2002; Innes *et al.*, 2005).

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8: THE ABUSE OF VULNERABLE ADULTS AND ADULT PROTECTION: WHAT WE KNOW FROM RESEARCH

Summary

Recognising abuse and knowing what action to take is of vital importance for professionals working with older people with mental health problems because they are at greater risk of abuse than other groups of older people. It is difficult to know how common elder abuse is in the UK but episodes of abuse have been reported in all settings, including people's homes, hospitals, sheltered accommodation and care homes. Training can improve staff recognition of abuse. There is very little information on the sorts of help that older people who have been abused would like.

Definitions of abuse

In comparison with child abuse, our knowledge about the reasons why elder abuse occurs and the steps that can be taken to prevent it remain extremely limited. The Department of Health (2000) defines abuse as:

> *A violation of an individual's human and civil rights by any other person or persons...Abuse may consist of a single act or repeated acts.*
>
> (Department of Health, 2000, p8)

However, there is still 'no standard definition of elder abuse within the UK public sector...and [the term] has no legal status and would not be recognized by many older people' (House of Commons Health Committee, 2004, p7).

Nevertheless, it is generally agreed that the main forms of abuse consist of:

- physical abuse, including hitting, slapping, pushing, kicking, misuse of medication, restraint, or inappropriate sanctions;

- sexual abuse, including rape and sexual assault or sexual acts to which the vulnerable adult has not consented, or could not consent or was pressured into consenting;

- psychological abuse, including emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from services or supportive networks;

- financial or material abuse, including theft, fraud, exploitation, pressure in connection with wills, property or inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits;

- neglect and acts of omission, including ignoring medical or physical care needs, failure to provide access to appropriate health, social care or

educational services, the withholding of the necessities of life, such as medication, adequate nutrition and heating; and

- discriminatory abuse, including racist, sexist, that based on a person's disability, and other forms of harassment, slurs or similar treatment.

Any, or all, of these types of abuse may occur deliberately or as a result of negligence or ignorance (Department of Health, 2002, p9). Furthermore, these categories are not mutually exclusive and there may be some overlap (Cooney and Howard, 1995). In some instances, the abuse may have begun with the onset of disability or illness in old age; in others it may be part of a pattern of domestic violence (Penhale, 2003).

How common is elder abuse?

Estimating the prevalence of elder abuse is difficult because of the likelihood of under-reporting. This may occur when the abused person is reluctant or unable to say what has been happening, when staff lack training in detecting abuse (McCreadie, 2001) or when staff identify abuse but their agencies' reporting and recording procedures act as barrier to further action being taken (Preston-Shoot and Wigley, 2002).

In comparison with the US where there is mandatory reporting of elder abuse, it is much harder to estimate how common it is in the UK. The only UK prevalence study remains that of Ogg and Bennett (1992). This suggested that up to five per cent of older people living in the community experienced verbal abuse and a further two per cent experienced physical or financial abuse. However, this may not be a comprehensive estimate as the study excluded people living in long term care and those who were very frail (Manthorpe *et al.*, 2004). Much higher prevalence rates of physical abuse have been reported in studies of older people referred to secondary health services (Homer and Gilleard, 1990; Compton *et al.*, 1997). However, it remains unclear as to how much of this variation is explained by differences in sample selection and how much it reflects the likelihood that some health and social care settings will have a higher prevalence of people who are abused than others. While the majority of abuse takes place in older people's own homes, calls to the *Action on Elder Abuse* helpline have been received from people in hospital, long term care and sheltered housing (Bennett *et al.*, 2000).

Who is at risk of elder abuse?

There is a major difference between being vulnerable to abuse and being at risk of it. As McCreadie (2002)points out, the rich widower in the early stages of dementia living on his own in a mansion flat may be *vulnerable* because of his dementia but he is at *risk* because of his wealth and isolation (p5). Research suggests that the risk of elder abuse is higher in the following situations:

- Older people with cognitive impairment are at greater risk of abuse than are older adults without cognitive impairment (Cooney and Howard, 1995; Lachs *et al.*, 1997; Shugarman *et al.*, 2003).

- Older people with depression are at greater risk of abuse, particularly neglect, than those who are not depressed (Dyer *et al.*, 2000).

- People who physically abuse another person have high reported levels of alcohol consumption (Homer and Gilleard, 1990; McCreadie *et al.*, 2000; Reay and Browne, 2001).

- Where relationships between those living together in a household have always been poor, there is a greater risk of abuse (Homer and Gilleard, 1990; McCreadie et al., 2000; Reay and Browne, 2001).

- While only a minority of carers abuse the person for whom they care, carers are more likely to be verbally or physically abusive when the person who is receiving care is physically and verbally abusive to them or if he or she has behavioural problems (Levin *et al.*, 1989; Levin *et al.*, 1994). It may also happen where carers feel they are not receiving adequate help (Cooney and Howard, 1995).

Helping staff recognise abuse

Changes to reporting systems since the introduction of *No Secrets* appear to have improved the monitoring systems for adult protection but work is still needed on establishing effective risk assessment tools (Manthorpe et al., 2004), particularly in the form of short easily completed screening instruments that can be used by staff in a variety of settings (Fulmer *et al.*, 2004). Barriers to the recognition of abuse identified by health and social care workers include: lack of clarity in what constitutes abuse (Taylor and Dodd, 2003); help in dealing with financial issues for people with dementia (Means and Langan, 1996); and the challenges of differentiating between lifestyle choice and neglect in terms of domestic hygiene (Pritchard, 2002) and sexual expression and abuse (Jeary, 2004). Training has been shown to be helpful in terms of helping staff to recognise abuse (Richardson *et al.*, 2002; Taylor and Dodd, 2003), although both studies identify that the issue of what to do when a colleague is suspected of abuse remains a source of concern.

Help for people who have been abused

There is very little information on what help people who have been abused would value. Research suggests that people need to be asked about the kind of help they want and their strengths in managing these situations (McCreadie, 2002). A US study suggested that older people were no less likely to be prepared to discuss intimate issues than younger people and that they valued the anonymity of telephone interviews and the chance of avoiding anyone else overhearing what they were saying by the use of closed questions to which they could answer yes or no (Acierno *et al.*, 2003). Some

older people who have been abused especially value the opportunity to attend a support group (Pritchard, 2003).

For those who have been the perpetrators of abuse, an education and anger management programme may be effective (Campbell Reay and Browne, 2002).

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