Unmet need and older people

Towards a synthesis of user and provider views

Lis Cordingley, Jane Hughes and David Challis

CONTENTS

FOREWORD

Unmet need has become a confusing and difficult concept for all concerned with community-based care. Confusion exists as to whether it relates to inadequate supply, poorly articulated demand, lack of responsiveness to demand or an interaction between the two. This paper seeks to explore ways of rendering user and provider perspectives less antithetical.

The paper covers two broad domains: areas of unmet need identified by older people and the response of the formal sectors to the issue of unmet need. Chapter 1 reviews commonly overlooked needs identified by older people. This is followed by reasons why older people may resist support or help. In Chapter 2, we describe studies that illuminate the processes by which social services departments identify and respond to the needs of older people. Chapter 3 suggests a number of alternative strategies for identifying unmet needs.

The paper was not commissioned as, nor designed to be, a comprehensive review of a highly complex issue. Rather, its purpose is to identify issues associated with the nature of unmet need, agency processes which are more or less likely to be associated with the identification of need, and ways in which a greater convergence could be achieved between user and provider perspectives.

The authors are grateful to Yasmin Khan for secretarial assistance.

1 INTRODUCTION

"What does *needing* help mean? Does it mean that the task could not be accomplished without help even to save one's life, or does it mean that it is nice to have help because it removes the fear of falling or accomplishes the task more quickly?"

> (Wenger, 1986, p. 72, emphasis in original)

"It's not that I *can't* bath myself, you see. It's just that I'm scared I might fall and then no one would know. I have had falls before."

> (Participant quoted in Cordingley, 1999, emphasis in original)

Unmet need is by no means a new issue, although it is one that has become more visible in the last decade. In 1970, Goldberg and colleagues found that, compared with those with little training, trained social workers perceived more problems, identified more needs and initiated more help than those with little or no training (Goldberg *et al.*, 1970). However, other studies identified the disparity of understanding between recipients and providers of services (Mayer and Timms, 1970; Rees, 1978). Need is not a neutral concept, and its assessment necessarily incorporates value judgements about what constitutes need as opposed to desire. Hence, perceptions of need are bound to vary depending on the position and motives of those making the judgement.

Wilkin and colleagues (1992) identify three broad approaches used to formally assess need.

- *The ideal standard*: such as the World Health Organisation's definition of health as complete physical, mental and social well-being.

- *The minimum level*: widely used in social and health policy but which ignores what other people define as real needs.

- *The comparative approach*: a compromise in that it extends minimum standards but relies on comparisons with other groups.

In relation to older people, Isaacs and Neville (1976) described 'unmet needs' as being present in older people if either (or both) of the following criteria are met: 'insufficient care to fulfil his basic requirements for food, warmth, cleanliness or security at a level at which he would have provided them for himself had he been fit to do so, or when care was provided only at a cost of undue strain to the relatives' (p. 81). The phrase 'undue strain' refers to the threat to physical, psychological and social well-being of those relatives as a result of caring for an older person. They also identified 'potential need', defined as the inability to perform for themselves some of the basic activities of daily living as a result of physical or psychological disease or disability. This differs from 'actual need' in that people have needs met by spouse, relatives, friends or existing services. Isaacs and Neville stressed the importance of recognising other needs such as financial security, a home, a constructive role in life and opportunities for social participation.

Davies (1977) has described need as a 'shortfall', the distance between a socially accepted and desired state and the current level of well-being. This definition is particularly helpful in today's world of outcome-oriented and evidence-driven services since it provides a basis for defining need based upon norms that may change with social standards.

There are a number of contextual issues to consider in relation to unmet needs of older people.

1   Because the largest group of those who use health and social services are older people, there is the danger of reinforcing a view of older people as needy. In fact, the vast majority of older people, even those over 80 years old, do not need help with personal care such as washing and bathing. Furthermore, much evidence cannot be assumed to be 'typical' (Wenger, 1987); for example, studies about carers of older people are over-generalised and assumed to indicate the norm; and secondary analyses of demographic statistics have to rely on conjecture about what it means to be old, rather than the reality. Indeed, the *range* of individual differences in all measures of status and performance increases with the age of the sample, thus the range of needs will be greatest in the oldest groups within any population (Bond *et al.*, 1995).

2   A discussion of (unmet) needs rather than (say) entitlements or legitimate expectations risks portraying older people as passive recipients of formal and informal sources of support, rather than as agents with the potential to organise resources from both formal and informal sources.

3   There is the possibility that needs are 'unmet' because of individual personal resistance to and preferences about support. This is rarely discussed formally within the policy-making arena.

2 OLDER PEOPLE'S PERSPECTIVES

Overlooked needs of older people

The issues raised are those identified by older people themselves and are summarised under headings covering individual circumstances, characteristics and types of need.

Needs arising from short-term illness

Most older people have few problems coping, even when living alone. In fact, living alone is a useful indicator of a person coping rather than being at risk, as is often assumed (Lubben, 1988). Systems of care tend to be concerned with long-term support needs and this is where much policy discussion is centred. However, short-term needs, such as those arising from brief illnesses may, without adequate intervention, lead to long-term problems. A report commissioned by the Anchor Housing Trust provided evidence that some acute short-term crises, such as illness, resulting in older people moving to residential care, could be avoided by increasing levels of appropriately targeted community-based support (Anchor Trust, 1996).

In a recent UK study of older people living in the community (Cordingley, 1999), participants were asked how they would cope should they become ill (with influenza, for example). It was found that, while the majority of those interviewed did manage with

the help of others, there were those whose household and social network structures made them vulnerable. Box 1 gives examples of statements made by individuals in that study. An important finding was that beliefs about ability to cope with brief illness did not depend either upon *size of social network,* nor the *frequency of contact.* In fact, many of those who express anxieties about coping with brief illness had larger network size than those who did not. It was the *types* of relationships available within those networks that were crucial (Cordingley, 1999).

Box 1 Responses of older people living at home to the question of how they would cope with an illness such as flu

"That's a question, love. I don't know. The friends I've got are all older than me."

"I don't know. My husband couldn't look after me. Neighbours I wouldn't like to ask unless absolutely necessary, they are young people."

"Very badly. The neighbour will do the shopping but it's very hard being alone."

"That would bother me. I have no one who would come and stay. I don't think about it. I don't know what I would do. My sister and I always looked after each other but she's got leukaemia so it's not possible."

"This would be a real problem for me. I would have to pay to go into a nursing home if I took ill."

"I'd have to manage alone I suppose, there's no one else. But that's a frightening thought. I just hope it doesn't come to it."

Source: Cordingley (1999).

People tend to rely on close female relatives (daughters, daughters-in-law and siblings) rather than friends should they fall ill (Lewis and Meredith, 1989; Rook, 1987). Thus, needs resulting from short-term illness disproportionately affect childless and unmarried people, and their specific needs are discussed subsequently.

Older people as carers

The vast majority of carers of older people are other older people who may have their own needs, independent of those stemming from their caring role. Seymour (1994) found that women, especially older women, looking after ill husbands do not identify themselves as 'carers' but view caring activities as part of their role as a wife. Although this is not a problem in itself, Seymour found that offers of help and support from services directed specifically at 'carers' were not recognised as relevant by married women.

There are other indications that the needs of older women caring for ill husbands are not always recognised. Restrictions resulting from their caring role meant that they might not be able to continue the social activities they once enjoyed. This is particularly important for women who, even when their husbands are well, are more likely to view female relatives and friends as their confidantes. Being married may create expectations in others that emotional and social needs are met, and consequently they are not addressed (Cordingley, 1999).

Reluctance to express dissatisfaction with their marital relationship may also lead to needs of older married people being unmet. In a study of older married women, those interviewed needed to present their relationships with their husbands as good. However, as the interviews progressed, they revealed their unhappiness at losing aspects of the relationships such as shared

activities, and the loss of contact with grandchildren and other relatives (Rose and Bruce, 1995).

For some older people, increasing frailty may mean that they have to relinquish a caring role. In one study, grieving the loss of role in caring for disabled children was found (Cordingley, 1999). Unlike others for whom the departure of their children may be symbolic of their increasing independence (Apter, 1995; Sidell, 1995), these people knew that their child's departure reflected their own inability to look after them, rather than representing the lessening needs of the child. The fact that this change had come relatively late in their lives meant that they had limited social networks to help them adjust and there was an unmet need for emotional support.

Single (never-married) older women

Single (never-married) women are eight times more likely than their married counterparts to live in residential or nursing care (Arber and Ginn, 1991). This occurs in spite of the fact that this group generally has the most friends and highest levels of contact with relatives compared with other older people (Cordingley, 1999). The higher proportion of single women who move into residential care, therefore, is less a result of late life social isolation than cultural expectations about who people can ask for help with personal care. Furthermore, with respect to assistance with tasks like cleaning, something for which it is considered inappropriate to ask friends, the lack of certain types of home care support may disproportionately affect single women. Most single women name siblings and friends as their key source of support, that is, people of the same generation, but, as one person observed: 'We will all end up needing help at the same time' (Cordingley, 1999).

Single people who have lived with a relative for most of their adult lives appear to be at further risk if that person dies or moves into residential care. If they were carers, they may have had less opportunity to develop or maintain broad social networks (Webb, 1992). Thus, they have neither the inter-generational close family ties of married and widowed women, nor the friendships that other single women may have created. It may be the case that the needs of this subset of single women are less visible than, for example, women who become widowed.

Since the contacts of single (never-married) people are predominantly the same generation as themselves, they are more likely to suffer from multiple bereavements (Kendig, 1986) and such losses have a proportionally greater impact on the size of the network. Additionally, single people (women in particular) are more likely than married or widowed people to have been carers of parents or siblings. This increases the likelihood that bereavement has a large impact additional to limitations on opportunities to create other social contacts. Finally, single status is also likely to be affected by the impact of divorce rates on the future ageing population. The needs of this group are rarely considered (Cain, 1988; Cordingley, 1999).

Need for a same-sex carer

There are times when professionals assume the care needs of older people are met when, in fact, the sex of the carer is problematic for the recipient. A woman speaks talking about her assessment for discharge from hospital:

> "They [hospital staff] assumed I get help from my sons but they have their own lives. Anyway there's lots I wouldn't want them doing."

Another said that, because she lived with her son, other staff did not realise her need for support, especially in relation to self-care. She had severe arthritis and had had a colostomy:

> "Getting dressed is hard, worse when I'm having a bad spell. Even though [son] lives here you can't ask him to help you get washed and that."

A single woman living with her two brothers worried about becoming ill because she would not like them to care for her:

> "I don't want to be in bed and an invalid. I wouldn't like my brothers to look after me. You need a woman."

These examples indicate that assessors of need must pay close attention to the feelings of the recipient about the appropriateness of the carer, and enable the recipient to discuss needs without the carer present (Cordingley, 1999).

Ethnicity and older people

Ethnicity is a complex and traditionally sensitive issue. Many studies and surveys of older people fail to consider it and it is possible that specific needs of certain groups are not met as a result. Ethnicity is sometimes confused with 'race'. For example, the UK Government Office for National Statistics does not include white people in categories of ethnic minorities. Groups of older people whose language, traditions and opportunities are quite distinct may thereby have these ignored (Gould, 1999). Differential patterns of morbidity exist between different groups of older people, particularly in coronary heart disease and severe mental

illness (OPCS, 1991; Wild and McKeigue, 1997). Furthermore, for ethnic minority older people, there are marked variations in access to and utilisation of services (Gould, 1999).

Many of the issues raised earlier in this paper are pertinent for ethnic minority older people. However, aspects of identity such as 'race' and culture *interact* with them, and services need to be sensitive to specific issues arising as a result. For example, being a first-generation immigrant to the UK has an impact on the number of peers available for support as people age. Also, the stereotyping of cultures such as family structures may mean that needs are unmet. Evidence suggests that, in some respects, the needs and expectations of older people whose country of origin is outside the UK are more like those of the host population than their previous compatriots.

Concerns exist regarding effective communication between professionals and ethnic minority elders. Beliefs and values can affect interpretation of illnesses such as depression, which may be influenced by extent of language skills and length of time in host country (Chan *et al*., 2000). Beliefs about feasibility and efficacy of rehabilitation can impede the effectiveness of this policy initiative (Ebrahim, 1996). As well as raising awareness about these issues, there needs to be research on current *good practice* if effective responses are to be made to the needs of ethnic minority older people.

Needs of long-term disabled people

Older disabled individuals can be separated into those disabled from being younger and those who become disabled in later life. Zarb's (1993) research on the former indicates that, in spite of some overlap, there are important differences between these groups. The 'disability career' of older disabled people tends to be neglected. A pattern identified by Zarb is a general physical

deterioration, which is more closely related to length of time since the onset of disability rather than ageing itself. This is independent of age and is termed 'premature ageing'. A higher incidence of arthritic and rheumatic problems exists, due, directly or indirectly, to the original disability.

Depression and older people

There are few health and social services responses that address the issues of loneliness and depression in older people (Wenger, 1990). General practitioners are less likely to refer depressed older people for specialist intervention compared with younger patients, in spite of evidence of beneficial outcomes (Bannerjee *et al.*, 1996). One possible explanation for this situation is that health-care professionals view depression in old age as inevitable and untreatable rather than as the result of a combination of personal and situational factors, and professionals need further training so that the condition is recognised.

Needs of older people in nursing and residential homes

It has been found that less than 2 per cent of staff working in residential and nursing homes had received any training in recognition of depression. Staff, including trained nursing staff, did not recognise depression in between 15 and 27 per cent of those assessed independently as depressed (Bagley *et al.*, 2000). Furthermore, even in those cases where it was recognised, treatment was not forthcoming. Given that depression is viewed as eminently treatable in older people (Heston *et al.*, 1992; Katona, 1994), this recent finding is of great concern.

Lack of stimulation in nursing homes has long been recognised. Activity patterns need to be based on the interests of the person

rather than on what is available within homes. A recent study of quality of life of older people in nursing and residential care (Godlove Mozley *et al.*, 2000) found that satisfaction with activities not only predicted satisfaction with the home, but also predicted survival. This study is one of the few to attempt to elicit opinions about needs from those diagnosed with mild and severe cognitive impairment, the inclusion of the views of whom is a key challenge for improving the delivery and quality of older people's services (Bond, 1999).

Need identification in primary health care

Older people are often reluctant to seek assistance from their general practitioners (Sidell, 1992). However, it is clear that many would like help, especially in dealing with chronic health problems. Tilston and Williams (1992) found that the annual health checks for people over 75 were viewed very positively by older people giving them an opportunity to discuss the management of symptoms, especially pain, and the need for information about living with chronic conditions. They argue that, rather than acting simply as a screening process, the over-75 health check could provide general practitioners with a valuable opportunity for supporting women in managing their own health, rather than acting as a simple screener. Cordingley (1999) similarly found that people would value the chance to discuss health needs. They preferred to talk to nurses rather than doctors, since they felt that this was 'not what the doctor was for'. There was a tendency to view visits to their general practitioners as important for acute illness but not for general questions about their health or ongoing concerns. Although the model of care provided by health visitors (illness prevention and management) might appear to be appropriate to meet these needs, few NHS trusts have health

visitor provision for older people, with most resources focused entirely on the under-fives (Woolstone and Ivings, 1994).

Needs missed by assessment instruments

Standardised assessment tools are used for planning of health and social services to meet the needs of older people as well as for establishing the criteria used to determine access to them. Assessing health, disability and support are complex processes, and there are issues of specific relevance to assessments of older people and their role in highlighting or underestimating their needs.

Health

Some methods of measuring health, such as mortality rates and service utilisation, are conceptually fairly simple. However, the past ten years have seen a move to incorporate subjective assessments of physical functioning and well-being. Although such scales may be useful in identifying older people's perspectives, they may, paradoxically, have the effect of underplaying the extent of their needs. Many authors have reported the phenomenon of older people with severely limiting illnesses or disabilities reporting good health (for example, Sidell, 1995). This was illustrated in a recent UK study of older people, which included a widely used health assessment schedule in which several items ask about the impact of illness on daily life, for example, the extent to which *pain or illness interferes with normal activities* (Cordingley, 1999). A pattern of response frequently occurred whereby individuals would obtain scores on the scale indicating good health in spite of severe pain or long-term disability. However, the reasons their health problems did not interfere with normal activities was because *they no longer*

engaged in such. For this group, high scores resulted from the fact that their low levels of activities had not recently changed rather than good health. The confounding of these two explanations meant that potential needs were hidden.

Health measurement tools are, like other scales, frequently developed and standardised on one section of a population and then used with another (Hunt and McKenna, 1993). This is particularly problematic when health assessment scales standardised on younger people are used to assess older people. Some items may simply be inappropriate for large numbers of older people (those asking about employment problems caused by illness, for example). More serious consequences may arise from the degree of sensitivity of indicators to change in older people. A widely used health status questionnaire (UK SF-36, constructed and standardised on adults under 65 years of age) was used to assess the benefits of cataract removal for older adults. The lack of significant difference between the SF-36 scores before and after treatment apparently indicated that the patients had not experienced any significant benefit from the treatment. However, both physiological measures (significant improvement in visual acuity) and detailed qualitative data supported the conclusion that the procedure was highly beneficial. The assessment tool was not sufficiently sensitive to changes and, had SF-36 scores alone been used, these benefits would not have been apparent (Hill and Harries, 1993).

Informal support and coping

Tools for assessing informal support have been strongly criticised in the past for assuming that levels of social contact (such as family size, household composition) were indicative of available help (Gottlieb, 1988; Wenger, 1989; Whelan, 1993). However, changes in social network patterns that occur with age mean

that instruments do not assess issues specific to meeting older people's needs (Mor-Barak and Miller, 1991). Differences between individuals are missed and, as discussed above, it is difficult for standardised instruments to determine whether a relationship should be viewed as a source of support or as a source of stress.

Appropriate use of standard measures

Given these criticisms of assessment tools, it is crucial that their use and performance are monitored in relation to older people. There is a very real danger that they could, directly or indirectly, result in services and treatments being denied to older people. Scales need to be developed specifically for older people, and for specific purposes. Additionally, it is essential that practitioners view data from health and social support scales as *indicators* rather than as *measures*. The key point here is that these scales add to, rather than replace, other salient pieces of information upon which decisions about access to treatment or care are based. Alone, they are not sufficient to establish the content of need.

Resistance to having needs met – attitudes and perspectives of older people

There are many reasons why older people may resist offers of support, and needs remain unmet as a result. Certain attitudes, experiences or belief systems can lead to perceptions of support being either unavailable or undesirable (Challis and Davies, 1986).

Experiences of poor quality of care or support

Resistance to help or support sometimes arises from previous negative experiences. For example, in the Cordingley (1999) study, one participant, who herself suffered from severe arthritis, cared

for her husband with advanced dementia. She had been offered, and had used, respite care for her husband. However, she felt the care was inadequate, and her husband would return disorientated and in a physically worse state than when he had left. Thus, in spite of clearly defined needs, knowledge of poor quality of services meant that these needs remained unmet. Older people frequently view provision of home care as problematic. It is often allocated on the basis of a person's disability, reflecting the concern to target resources on the most disabled. However, an unintended consequence of such a means of targeting by activity may be to undermine older people's attempts to mobilise social contact and practical support. This is of particular concern in view of the increasing emphasis placed on rehabilitation for older people in order to improve their health and social functioning (Department of Health, 1997; Cm. 4169, 1998). Additionally, Rose and Bruce (1995) suggest that gaps in social care, such as the lack of cleaning support, are particularly hard for women who may feel less inclined to invite people to their 'dirty' houses and thus become more isolated. Farquhar *et al.* (1993) found that asking older people whether or not they would like additional help from social services does not produce an accurate assessment of need. People are aware of the limited tasks performed by the service. If, instead, they are asked whether there are specific tasks they need help with, perceived demand for help is much greater.

Older people have reported frustration with health professionals who appear to dismiss their concerns as being due to age itself. Koch and Webb (1996) reported that older people's views of themselves are often at odds with those of the people caring for them. They reported interactions that revealed reluctance on the part of the health professionals to treat the older person on the basis of their individual requirements. Rather,

they demonstrated a generalised approach to care based on their assumptions about what older patients need. Sidell (1992) also found older people were left frustrated and disempowered by general practitioners' responses, which attributed symptoms to age. Health professionals frequently overlook the sexual health needs of older people, whether by denial or negative perceptions (Webb and Cordingley, 1999).

Need for self reliance

Many older people resist taking up offers of support, and express their need to maintain self-esteem and feelings of self-reliance. For some, accepting help threatens a sense of personal autonomy and independence. This is more likely for those with limited access to close emotional ties but it also perhaps reflects life experiences in which help was not available and long-held beliefs about the importance of coping independently of others. Although some older people see self-reliance as a virtue, these are often the people most likely to conceal difficulties (Challis and Davies, 1986; Wenger, 1993).

Gender and class influences are apparent in older people's assessments of their own needs (Arber and Evandrou, 1993; Dalley, 1993; Hockey and James; 1993). For example, women may find admitting the need for domestic help harder than men if they have been used to taking responsibility for those tasks (Qureshi and Walker, 1989). People find offers of domestic help more threatening if they have been used to having responsibility for domestic tasks throughout their lives, whereas those women who have previously employed others to do household tasks may not find it problematic (Hockey and James, 1993).

For some older people, admitting needs resulting from increasing frailty or chronic illness may feel like a loss of status associated with the identity of an older person. People may resist

the idea that they are getting to that stage in life. Additionally, accepting support or help from some services may feel stigmatising because of means testing (Arber and Evandrou, 1993). Health care, on the other hand, is seen as a resource to which there is an entitlement, and articulation of need is legitimised. Resistance to support may indicate need to preserve a public coping face, beyond the scrutiny of public bodies.

Fear of overburdening relatives and friends

Many older people are anxious to protect their relationships with friends and relatives, and try to avoid making demands even when they acknowledge their need for help (Cordingley, 1999; Jerrome, 1990). It is therefore crucial to differentiate between those in the social network viewed by the older person as appropriate and acceptable sources of help. Professionals may assume support is available to them from family members when, in fact, there may be reluctance on the part of the older person to 'burden' those relationships with requests for help. In these circumstances, having needs met by formal systems may be protective of social relationships which otherwise may be put at risk through demands placed upon them. Box 2 provides illustrations of these dilemmas.

Box 2 Older people's fears of overburdening relatives and friends

"I would never want my sons to be obligated to me like I was to my mother. I never ask to go and see them. I wait until I'm asked. Then I know I'm wanted. I know cos it's how I felt about my mum. I don't want my sons to feel like that about me."

"Friends don't want you if you're not well but my nurse lets me cry. I want nothing. She sits and listens ... she's very valuable, she counsels me."
Source: Cordingley (1999).

---

3 UNMET NEED: THE RESPONSE OF THE FORMAL SECTOR TO ACCESS AND ASSESSMENT

This chapter considers the responses of the formal sector to the needs of older people. Several factors are likely to influence the response, and initial access to services and the identification and specification of need are particularly important.

Unmet needs are likely to arise in part from variations in the degree to which provider agencies differ in terms of 'who gets what'. The main issues arising are those relating to consistency and equity both within and between agencies such as health and social services. Here we identify some aspects particularly relevant to social care. These include issues of access, need identification and provision of care. The studies cited are based upon very substantial proportions of social services departments in England, up to 80 per cent, and can therefore be considered as a representative picture. For that reason a summary of each is included here.

Pathways into care and service receipt

Eligibility criteria for social services for older people in England

As part of the implementation of the community care reforms, individual local authorities were required to develop eligibility

criteria in order to assist in the targeting of services on those in greatest need. The eligibility criteria are derived in their present form from the White Paper, *Caring for People* (Cm. 849, 1989). Local authorities also used them as a means of financial control, an approach endorsed by the Audit Commission (1993). After the implementation of the community care reforms, it was noted that eligibility criteria were not always being consistently interpreted and applied or linked to the allocation of resources (Cm. 4169, 1998; Department of Health, 1995, 1998).

Four years after the introduction of the community care legislation, the Personal Social Services Research Unit (PSSRU) undertook a study of eligibility criteria for services for older people. All local authorities in England were asked to supply details of these and a response rate of over 70 per cent was achieved. The methodology employed to analyse these documents has been described elsewhere (Hughes *et al.*, 1997). In terms of exploring how local authorities conceptualise and respond to unmet need, four of the research findings are of particular interest.

1 The contents of documents relating to eligibility criteria were explored. Nine domains of potential need were identified: physical health, mental health, activities of daily living, instrumental activities of daily living, the role of informal carers, risks, finance, housing and the existence of support networks in the community. The first six were judged to be of particular significance in determining eligibility for assessment and service provision, yet they were noted in documentation provided by only 64 per cent of respondents.

2 The extent to which local authorities had separate criteria to determine eligibility for residential and home-based care

was examined. The majority (64 per cent) had combined criteria. However, in terms of making an appropriate response to unmet need, separate criteria for the two forms of care are indicative of a more targeted approach to the allocation of scarce resources.

3   Two distinct ways of defining eligibility were identified as described in Box 3. Overall, a graded approach was more often found when local authorities had separate eligibility criteria for domiciliary and residential care services, whereas a threshold approach was often associated with authorities that had a single combined set of criteria for all services. A single set of criteria determines whether or not an older person receives an assessment of need as part of the care management process and is therefore necessarily less specific than separate criteria. Both graded and separate criteria are likely to be much more explicit about the relationship between particular needs and expected levels of response, and therefore also more amenable to the development of indicative care packages discussed below.

4   The degree of coverage, structure and detail of information included in each of the identified domains was adjudged and, if appropriate, whether or not standard measures had been used. These criteria were selected and ranked in the hierarchy shown in Figure 1 to reflect quality of eligibility criteria. The further up the hierarchy, the greater the possibility that eligibility criteria could provide an equitable and transparent means of deciding who should receive publicly funded services. Moreover, eligibility criteria meeting this standard would be more reliable in the sense that more consistent judgements could be made about the

relative needs of individuals or groups. It was interesting to note that no respondents used standard measures when appropriate and only 6 per cent met all the remaining criteria of coverage, detail and structure.

Box 3 Concepts of eligibility

- *Graded eligibility*: an approach to service provision that explicitly links levels of need to a series of defined levels of care.

- *Threshold eligibility*: an approach to service provision that makes a binary distinction as to whether a person's level of need or combination of need is sufficient to give them access to a service.

Source: Hughes *et al.* (1997).

Figure 1   Composition of domains
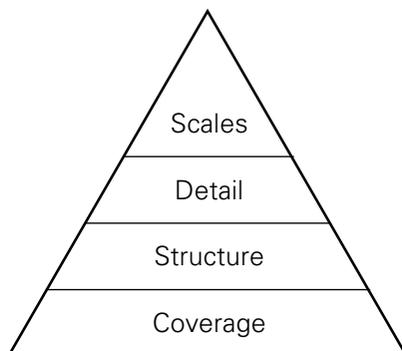
Source: Challis *et al.* (1997a).

Assessment approaches in social care of older people

A similar approach was employed in a second PSSRU study (Stewart *et al.*, 1999). This examined assessment approaches

for older people receiving social care from a sample of 50 social services departments, social work departments, and health and social services boards in the UK in 1995. As with the previous study, although the focus was on assessment documents for older people, the majority were generic to all service user groups. In brief, an analysis of the documents was undertaken using 33 assessment areas or domains derived from the Minimum Data Set/Resident Assessment Instrument (Morris *et al.*, 1990, 1995). These are detailed in Box 4. This is a US Federal Government mandated assessment tool for use in care homes, which has been subsequently developed for use in the community.

A number of findings are relevant in respect of this exploration of how local authorities conceptualise and respond to unmet need.

1   Twenty of the 33 domains were covered in more than 80 per cent of documents. These were: six activities of daily living items (dressing, mobility, bathing, transfer, toileting and feeding); four instrumental activities of daily living items (food preparation, housework, management of medication and shopping); communication; disease/health conditions; vision; cognitive impairment; depression; carer needs; social activity; home environment; financial information; and degree of participation in the assessment. It was concluded that these were core items within the assessment process.

2   This analysis of documentation demonstrates considerable variance in the amount of detail specified. This was apparent in two guises. Only 24 per cent of the assessment forms were used jointly by health and social services. While a number of assessment forms prompted for specialist assessment to be undertaken by health staff, the extent to which this occurred was unclear. Without this, there is a

Box 4 Assessment domains

Functional domains	*Cognitive/mood/psychosocial domains*
ADL: dressing	Cognitive patterns
ADL: mobility	Depression/anxiety/mood state
ADL: bathing	Social/recreation activity
ADL: transfer	Behaviour patterns
ADL: toileting	Customary routine (life preference)
ADL: feeding	
ADL: grooming	
IADL: prepare food	*Social environment domains*
IADL: housework	Home environment
IADL: manage medication	Participation in assessment
IADL: shopping	Carer needs/support given
IADL: manage money	Financial information
IADL: laundry	*Clinico-medical domains*
IADL: prepare hot drinks	Disease/health conditions
Communication/ hearing patterns	Nutritional status
Vision patterns	Medication details
Continence/related appliances	Skin condition/footcare
	Treatment/rehabilitation received
Rehabilitation potential needs	Dental status

Notes: ADL = activities of daily living; IADL = instrumental activities of daily living.

Source: Stewart *et al.,* 1999.

danger that information essential to elicit unmet need may not be routinely generated within an assessment. The research of Stewart and colleagues (1999) provided some evidence of this. For example, while depression, anxiety and mood state were noted in over four-fifths of assessment tools, they were detailed in only 4 per cent. As Stewart *et al*. noted, this is of particular concern given the high incidence of depression in social services home care populations (Bannerjee and MacDonald, 1996).

3   The documents vary greatly in the extent to which they were structured. While the majority were structured, at least in some of the domains, a few were short and unstructured. Supposedly, this permits the content of the assessment to be guided by the emerging needs and problems, and enables the user to define their need. However, such an approach could also result in a lack of consistency in assessing need because it also offers scope for assessor bias and variance.

Overall, it appeared that professionally relevant standardisation would be a desirable trend for the future development of assessment schedules, particularly with the variety of different staff with different training and professional socialisation experiences who would be expected to undertake the assessment of need. Such an approach is essential to further the goal of more equitable allocation of resources following an assessment of need.
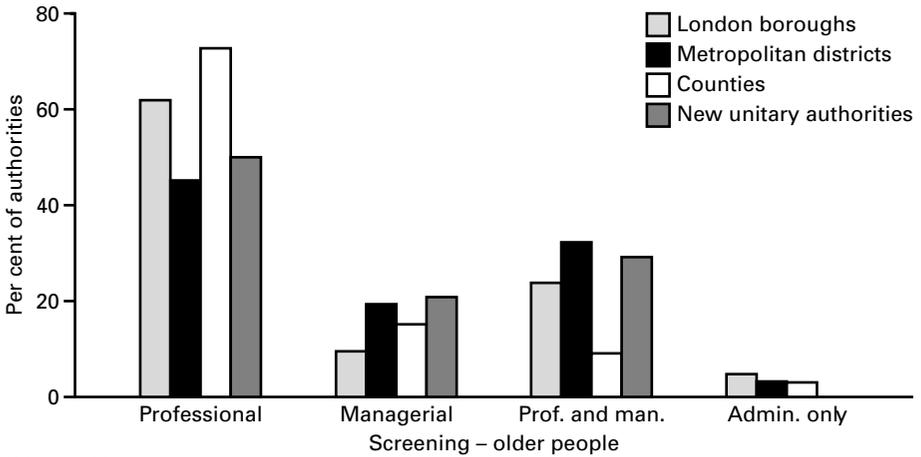
Care management

A programme of research to evaluate the different forms, types and models of care management for older people and those with

mental health problems is currently being undertaken by PSSRU (Challis *et al.*, 1999). A national survey of local authorities in England in 1997 elicited a response rate of 84 per cent. This information provides an insight into how local authorities respond to requests for assistance.

- Authorities were asked which staff groups were responsible for the screening of referrals. In older people's services, over 80 per cent of respondents indicated that professional staff were involved. Aggregate groupings were compiled to analyse the combinations of the three staff groups involved: professional, managerial and administrative. Figure 2 demonstrates that screening for services was more likely to be undertaken by professional staff in counties and London boroughs. Thus, local authorities demonstrate considerable diversity with regard to the staff designated to respond to initial requests for assistance and this further manifests itself in authority types.

- This variability is further reflected in guidance for screening and assessment of need. Respondents detailed a variety of written procedures, for example, eligibility criteria for assessment and service provision, and matrices to assist staff in screening requests for assessment.

- Similar diversity was also apparent in the approach of local authorities to the assessment of need. Almost half of respondents reported two levels of assessment for older people and a minority (14 per cent) had one level. Figure 3 suggests some differences between authority types. Counties were more likely to have one or two levels of assessment, and London boroughs and metropolitan districts were more likely to have two or more.

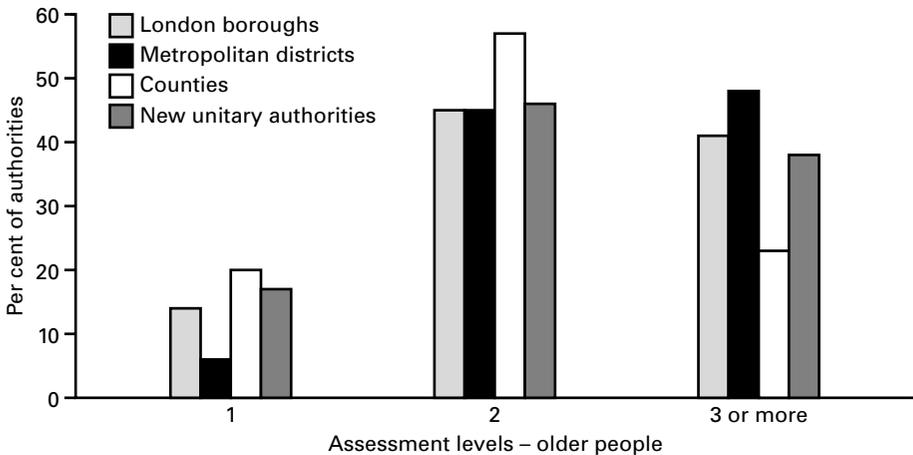## Figure 2   Staff groups responsible for screening of referrals – aggregate groupings

Note: *N* = 109.
Source: Challis *et al.* (1999).

Figure 3   Level of assessment by type of authority

Note: *N* = 107.
Source: Challis *et al.* (1999).

Pathways into care – policy and practice imperatives

Care management has 'a pivotal role as the setting where the integration of social and economic criteria must occur at the level of service provision, where the balancing of needs and resources, scarcity and choice must take place' (Challis, 1992). Assessments of need are made within a framework of limited financial resources. In spite of the fact that the NHS and Community Care Act (1990) is founded upon a 'needs-led', consumer choice perspective (Cm. 849, 1989), the reality is that those agencies providing care are restricted by the priorities set by their funding authorities. This tension means that, even when needs are defined and recognised by social services departments, they may remain unmet as a consequence of budgetary constraint, as was evidenced in the Gloucester judgement (*The Guardian*, 1997). It is within this context that the local authorities make decisions about the allocation of resources in respect of unmet need.

Currently, findings from research suggest that there is marked variability in both the process and content of assessment of need by local authorities (Challis *et al.*, 1999; Stewart *et al.*, 1999). Moreover, there are a plethora of arrangements and procedures by which adults access help as evidenced by the application of eligibility criteria and arrangements to screen people to determine their entitlement to assessment within the social services department (Challis *et al.*, 1997b, 1999). While there is evidence that local authorities have begun attempts to assure quality in these key processes (Challis *et al.*, 1999), the argument for greater consistency is irresistible on the basis of the research findings. The extent to which the proposals for change outlined in the White Paper *Modernising Social Services* (Cm. 4169, 1998) will address these issues is not known. However, as part of the 'Fair Access to Care' initiative, central government will specify for local authorities the principles they should follow when applying

eligibility criteria. Moreover, local authorities will be required to demonstrate consistency in the way every person's needs are assessed and clear objectives in all aspects of care management including initial screening and assessment.

Performance measurement

The emergence of a national performance framework for social services is likely to accelerate the development of local performance indicators. These may contribute to greater access through making the issue more transparent. One agency developed performance measurement for older people's services where aspects of unmet need were conceptualised as the difference between actual and expected responses by services. Examples of performance indicators which specifically address access might include the proportion of ethnic minority elders in receipt of certain services and the age-specific proportion of the ethnic minority in the area (Challis and Warburton, 1996).

Problems of providers

Problems of unmet needs for providers may arise from tensions both within service agencies and between agencies. The separation between the administration of health and social care in the UK results from historical and bureaucratic divisions rather than being based on clear theoretical perspectives (Challis, 1998; Challis et al.,1991; Sidell, 1993). For older people, the logic of this situation is highly questionable given the fact that they tend to assess their health using functional criteria (that is, their ability to perform tasks) rather than medical ones. In a study of people who had recently been discharged from hospital, some were receiving little or no support either from health or social services. Inter-agency conflict between the two services about what type

of care a person required and who was responsible for providing it could lead to the needs of some not being met (Sidell, 1995). This may result in them having to leave their homes in order to be supported by family or to enter residential/nursing homes (Anchor Trust, 1996). Conversely, it has been shown that different ways of conceptualising and organising social and health care can result in people being able to stay in their own homes for longer periods (Challis and Davies, 1986; Challis *et al.*, 1995).

The division of social and health services has significant practical implications for older people (Challis, 1998). Although aspects of unmet need associated with current boundaries may be addressed by the development of partnership initiatives between health and social care (Cm. 4169, 1998; Department of Health, 1998), there may emerge new unmet needs from new boundaries between acute and long-term care.

4 ALTERNATIVES APPROACHES TO UNDERSTANDING NEEDS

In Chapter 1, several factors that may influence the presentation or articulation of need by the user were considered. Important factors included the setting in which need occurs; the transfer of the experience of previous attitudes and experiences onto current help seeking; the particular form of need, such as depression; the extent and quality of social networks; and personal characteristics such as ethnicity. In Chapter 2, some recent work on access and assessment, and determinants of entry to need-meeting services is considered. It would seem that greater transparency and explicitness over the domains and content of eligibility and assessment could facilitate a more shared understanding of needs, and contribute to greater equity. This could enable a more helpful debate over issues of unmet need by providing a shared coherent framework for discussion.

This chapter examines ways in which greater convergence between user and provider views might occur, or in which provider variance in need identification might be reduced.

Approaches that link user and provider perspectives

There are examples of users and providers of care defining priorities together in order to meet needs more fully. O'Boyle *et al.* (1994) developed the Schedule for the Evaluation of Individual

Quality of Life (SEIQoL). Unlike other quality of life measures, in which the person constructing the scale decides the domains, the SEIQoL is based on those aspects that the respondent views as the most important. This technique allows for a systematic assessment of quality of life while still incorporating older person's views.

Similarly, Brown and Gillespie (1992) described ways in which health professionals (in this case, occupational therapists) negotiate treatment priorities with older people in order to meet their specific needs. Rather than concentrating solely on self-care tasks, the therapists discuss the patients' priorities and focus on those aspects that enable people to maintain other important areas, such as re-integrating into their social environment.

Assessing attitudes to professional and informal support

Little is known, either from formal or informal sources, about the decision-making processes used by older people in negotiating help (De Ridder and Schreurs, 1996; Eckenrode and Wethington, 1990). Cordingley used a technique called 'Q methodology' with older people to explore their attitudes to receiving support from others (Cordingley, 1999; Cordingley *et al.*, 1997). One objective was to investigate attitudes and beliefs that made seeking help more or less likely. From the data, five different 'accounts' or perspectives emerged each indicating different priorities. For example, one account emphasised the need to be self-reliant and maintain autonomy in decision making, and another stressed the importance of not jeopardising close relationships by over-burdening others. The remainder revealed how having needs met by relatives and friends reinforced friendships and emotional ties. Assessments of need that help to identify perspectives of older people would mean that support from the formal services could

be tailored in a way that did not undermine self-esteem, or compromise important relationships. This is a long-standing theme, evident in the work of Abrams (1977).

Approaches that predict potential need

Wenger and her colleagues have developed a system of categorising the *support* networks of older people based on three factors: availability of local close family members; the level of involvement with family, friends and neighbours; and the degree of involvement with wider community and voluntary groups (Scott and Wenger, 1995; Wenger, 1989, 1993). The five network types identified were: the 'local family dependent' network; the 'locally integrated' support network; the 'local self-contained' support network; the 'wider community focused' network; and the 'private restricted' type. An advantage of the longitudinal nature of this work was that Wenger and her colleagues were able to monitor changes and shifts in people's support networks over time. They found that some changes were more likely than others as a result of, say, ill-health. For example, transfer to residential care was more likely for those with a 'local self-contained' support network. Those with a 'private restricted' support network had low expectations of help should they need it. An ability to classify support networks means that gaps in support could be identified, and needs of older people predicted and met more effectively.

Lessons from overseas

More explicit definitions and greater consistency in eligibility criteria may enhance both equity and comprehensibility. In Australia, the process of determining eligibility for nursing home care is part of a more standardised screening and assessment process (Challis *et al.*, 1995, 1998). Decisions relating to the level

of care required by an older person in institutional care are made by the application of graded eligibility criteria, which are designed to ensure that those eligible for a particular level of service receive it and which determine the level of financial reimbursement received by the establishment for their care (Department of Community Services and Health, 1991).

In the New Zealand reforms of the early 1990s, eligibility for services was separated from the assessment process and the Government developed in conjunction with service users a document that describes what is required for high quality, needs-led assessment. Great emphasis was placed on assessments being needs and not service led, and comprehensive assessments encompassed the following areas: mobility, personal care, domestic/household management, education, training, employment, housing, and opportunities for personal and social development (New Zealand Ministry of Health, 1994).

Recent experience of the provision of services in British Columbia is relevant to considering how perceptions of need between professionals and the broader public might be reconciled. Eligibility for service was determined by health and not social care criteria: the diagnosis of a chronic medical condition. Concurrently, there were low-cost preventative services which potential service users could access themselves without recourse to procedures to determine eligibility for service and assessment of need (British Columbia Ministry of Health, 1992). The potential benefits of this emerge from greater equity with improved access, which incorporates a client-driven definition of need, as well as lower assessment costs for public agencies.

In a similar vein, many US states, and also long-term care insurance providers, employ impairment in activities of daily living as an indicator of need and eligibility for service (Liu and Cornelius, 1991). Although the price of such indicators may be a higher level of false positives (access given to service when need is not

present), the gain is that it is more clearly understood by both service users and providers.

Indicative care packages

In 1997, PSSRU completed a review of the emerging use of care packages within the NHS as a basis for planning and delivering community-focused care (Challis *et al.*, 1997c). A typical indicative care package might describe the level of services likely to be associated with a particular level of dependency, or potential need. Indicative care packages were defined in the review as 'a cluster of services provided to an individual or types of individual based upon decisions about their internal structure and cohesiveness' (Challis *et al.*, 1997c, p. 54). They span health and social care, and are an example of an integrated approach to service provision that produces greater standardisation of response.

The authors concluded that indicative care packages offer a meaningful definition of response to need, understood by recipients and providers alike. Furthermore, they provide a basis for realistic dialogue between older people and agencies so that expectations may converge. They could be used both for planning and for publicity informing potential users about services and rendering service eligibility more intelligible. This approach contrasts with the frequently observed pattern of service receipt, described as 'a random service mix' (Challis *et al.*, 1997c, p. 54). The development of this approach would need to take account of two main problems of community care: reconciling dependency-generated needs with the preferences of the service user and mediating the influence of factors that affect the need for care, such as the level of informal care and the type of housing stock.

Components of need assessment

The description of potential need used by Isaacs and Neville (1976), in terms of the interval of time between episodes of required assistance, offers a way of clustering need shortfalls which is meaningful to service providers and service users alike. There were three areas of potential need: critical interval needs (such as toileting), short interval needs (such as meal preparation) and long interval needs (such as shopping). The analysis of the shortfall between what is provided and required in these domains can be reliably used by assessors, and is readily understood by service users (Challis, 1981; Challis and Davies, 1986; Challis *et al.*, 1995). This can be coupled with specific enquiry to service users into the reliability, sufficiency and effectiveness of the help provided in each of these domains (Challis, 1981) to provide a framework within which a dialogue between provider and user can take place. A more standardised approach to eligibility and assessment, more consistent across the country, could also do much to clarify the degree of shared understanding between older people and service providers.

5 CONCLUSIONS

In a short review of the vast literature relating to the concept of unmet need in respect of older people, it is impossible to capture all the salient points. However, the findings of this paper suggest that the following issues are particularly pertinent.

- The concept of need used inappropriately may reinforce stereotypes of older adults as passive, dependent or needy.

- Failure to meet short-term needs has long-term consequences, for individuals and for services providing care and support.

- Health assessment instruments frequently underestimate the needs of older people and, used inappropriately, ultimately might lead to people not qualifying for treatment or care.

- Criteria to determine eligibility for care vary widely between local authorities. There is a lack of standardisation across authorities responsible for providing care and variability in processes used to determine eligibility for care.

- Assessment approaches vary markedly across local authorities and are likely to be less responsive to certain needs of older people, such as depression.

- There is a need for greater consistency in eligibility criteria and assessment approaches used by social services agencies.

- Looking at how other countries assess needs and implement care packages gives useful insights into alternative strategies.

- The provision of appropriately targeted services could promote feelings of independence and enhance people's own coping strategies.

- Criteria for assessing shortfall, the gap between required and received responses to particular domains of potential need, can be specified to offer a close convergence between user and provider perspective.

- Creative approaches to assessing needs that incorporate older people's perspectives would allow more effective targeting of assistance.

BIBLIOGRAPHY

Abrams, P. (1977) 'Community care: some research problems and priorities', *Policy and Politics,* Vol. 6, pp. 125–51

Anchor Trust (1996) *What Older People Want: a Manifesto on Long-term Care for Independence and Security in Later Life*. Oxford: Anchor Trust

Applebaum, R.A. and Austin, C.D. (1990) *Long-term Care Case Management: Design and Evaluation*. New York: Springer

Apter, T. (1995) 'Psychological developments in midlife women', unpublished paper presented to the British Psychological Society's Psychology and Women Conference, 7–9 July, Leeds

Arber, S. and Evandrou, M. (1993) 'Mapping the territory', in S. Arber and M. Evandrou (Eds) *Ageing, Independence and the Life Course*. London: Jessica Kingsley

Arber, S. and Ginn, J. (1991) *Gender and Later Life: a Sociological Analysis of Resources and Constraints*. London: Sage

Audit Commission (1993) 'Taking care: progress with care in the community', *Health and Personal Services Bulletin,* No. 1, December. London: HMSO

Bagley, H., Cordingley, L., Burns, A., Godlove Mozley, C., Sutcliffe, C., Challis, D. and Huxley, P. (2000) 'Recognition of depression by staff in nursing and residential homes', *Journal of Clinical Nursing*, Vol. 9, pp. 445–50

Bannerjee, S. and Macdonald, A. (1996) 'Mental disorder in an elderly home care population: associations with health and social service use', *British Journal of Psychiatry,* Vol. 168, pp. 750–6

Bannerjee, S., Shamash, K., Macdonald, A. and Mann, A. (1996) 'Randomised controlled trial of effect of intervention by psychogeriatric team on depression in frail elderly people at home', *British Medical Journal,* Vol. 313, pp. 1058–61

Barrera, M. (1986) 'Distinctions between social support concepts, measures and models', *American Journal of Community Psychology*, Vol. 14, No. 4, pp. 435–47

Bond, J. (1999) 'Quality of life for people with dementia: approaches to the challenge of measurement', *Ageing and Society*, Vol. 19, No. 5, pp. 561–99

Bond, L., Cutler, S. and Grams, A. (1995) *Promoting Successful and Productive Ageing*. Thousand Oaks, CA: Sage

Bowling, A. (1991) *Measuring Health: a Review of Quality of Life Measurement Scales.* Milton Keynes: Open University Press

British Columbia Ministry of Health (BCMH) (1992) *Case Manager Guidebook*. Victoria, BC: Continuing Care Division, Ministry of Health

Brown, K. and Gillespie, D. (1992) 'Recovering relationships: a feminist analysis of recovery models', *The American Journal of Occupational Therapy*, Vol. 46, pp. 1001–5

Cain, S.B. (1988) 'Divorce among elderly women: a growing social phenomenon', *Social Casework: The Journal of Contemporary Social Work*, Vol. 69, pp. 563–9

Challis, D. (1981) 'The measurement of outcome of social care of the elderly', *Journal of Social Policy,* Vol. 10, pp. 179–82

Challis, D. (1992) 'Community care of elderly people: bringing together scarcity and choice, needs and costs', *Financial Accountability and Management*, Vol. 8, No. 2, pp. 77–95

Challis, D. (1998) 'Integrating health and social care: problems, opportunities and possibilities', *Research Policy and Planning,* Vol. 16, No. 2, pp. 7–12

Challis, D. and Davies, B. (1986) *Case Management in Community Care*. Aldershot: Gower

Challis, D. and Warburton, R. (1996) 'Performance indicators for community-based social care: from theory to practice', *Care Plan*, Vol. 2, No. 4, June, pp. 19–24

Challis, D., Darton, R., Johnson, L., Stone, M. and Traske, K. (1991) 'An evaluation of an alternative to long-stay hospital care for frail elderly patients: I. The model of care', *Age and Ageing*, Vol. 20, No. 4, pp. 236–44

Challis, D., Darton, R., Johnson, L. and Traske, K. (1995) *Care Management and Health Care of Older People*. Aldershot: Ashgate

Challis, D., Gill, J., Hughes, J. and Stone, S. (1997a) *Eligibility Criteria for Social Services for Older People in England*. Research Briefing. London: Age Concern

Challis, D., Darton, R., Hughes, J., Stewart, K. and Weiner, K. (1997b) 'Mapping and evaluation of care management arrangements for older people and those with mental health problems', outline of a research project funded by the Department of Health, P25, PSSRU, Universities of Kent and Manchester

Challis, D., Hughes, J., Schneider, J., Carpenter, I. and Huxley, P. (1997c) 'Effective information and technology support for community focused healthcare. An evaluation of the requirement for national consistency in the definition of care packages', Discussion Paper 1310/M004, PSSRU, Universities of Kent and Manchester

Challis, D., Darton, R., Hughes, J., Stewart, K. and Weiner, K. (1999) 'Mapping and evaluation of care management arrangements for older people and those with mental health problems. An overview of care management arrangements', Discussion Paper 1519/M009, PSSRU, Universities of Kent and Manchester (not publicly available)

Chan, A., Challis, D. and Wong, L. (2000) 'Replicating the Hong Kong Chinese Geriatric Depression Scale in Manchester: some cultural considerations', Discussion Paper 1614/M017, PSSRU, University of Manchester (not publicly available)

Cm. 849 (1989) *Caring for People: Community Care in the Next Decade and Beyond*. London: HMSO

Cm. 4169 (1998) *Modernising Social Services. Promoting Independence, Improving Protection, Raising Standards*. London: The Stationery Office

Cordingley, L. (1999) 'Relationships between health, social support and independence in older people: a study using the SF-36 and Q methodology', unpublished PhD thesis, University of Manchester

Cordingley, L. and Webb, C. (1997) 'Independence and ageing', *Reviews in Clinical Gerontology*, Vol. 7, pp. 137–46

Cordingley, L., Webb, C. and Hillier, V. (1997) 'Q methodology', *Nurse Researcher*, Vol. 4, No. 3, pp. 31–45

Dalley, G. (1993) 'Caring: a legitimate interest of older women', in M. Bernard and K. Meade (Eds) *Women Come of Age: Perspectives on the Lives of Older Women*. London: Edward Arnold

Davies, B. (1977) 'Needs and outputs', in H. Heisler (Ed.) *Fundamentals of Social Administration*. London: Macmillan

Day, A.T. (1991) *Remarkable Survivors: Insights into Successful Ageing among Women*. Washington, DC: Urban Institute Press

Department of Community Services and Health (DCSH) (1991) *Aged Care Reform Strategy: Mid-term Review 1990–1*. Report. Canberra: Australian Government Publishing Service

Department of Health (1995) *Partners in Caring – Fourth Annual Report of the Chief Inspector of Social Services*. London: Department of Health

Department of Health (1997) *Better Services for Vulnerable People*. EL(97)62, CI(97)24. London: Department of Health

Department of Health (1998) *Partnership in Action (New Opportunities for Joint Working between Health and Social Services).* Discussion Document. London: Department of Health

De Ridder, D. and Schreurs, K. (1996) 'Coping, social support and chronic disease: a research agenda', *Psychology, Health and Medicine*, Vol. 1, pp. 71–82

Ebrahim, S. (1996) 'Ethnic elders', *British Medical Journal,* Vol. 313, pp. 610–13

Eckenrode, J. and Wethington, E. (1990) 'The process and outcome of mobilising social support', in S. Duck (Ed.) *Personal Relationships and Social Support.* London: Sage

Farquhar, M., Bowling, A., Grundy, E. and Formby, J. (1993) 'Elderly people's use of services: a survey', *Nursing Standard*, Vol. 7, No. 47, pp. 31–6

Gibson, C.H. (1992) 'A revised conceptualisation of social support', *Journal of Clinical Nursing*, Vol. 1, pp. 147–52

Godlove Mozley, C., Sutcliffe, C., Bagley, H., Cordingley, L., Huxley, P., Challis, D. and Burns, A. (2000) 'The quality of life study: outcomes for older people in nursing and residential homes', unpublished report presented to the NHS executive, Department of Health

Goldberg, E.M. (1970) *Helping the Aged: a Field Experiment in Social Work.* London: George Allen and Unwin

Gottlieb, B.H. (Ed.) (1988) *Marshaling Social Support.* Thousand Oaks, CA: Sage

Gould, M. (1999) 'Care of black and ethnic minority elders', in S.J. Redfern and F. Ross (Eds) *Nursing Elderly People* (3rd edition). Edinburgh: Churchill Livingstone

(The) Guardian (1997) 'Put care back into the community', Leader comment, *The Guardian*, 21 March, p. 19

Henwood, M. (1993) 'Age discrimination in health care', in J. Johnson and R. Slater (Eds) *Ageing and Later Life.* London: Sage

Heston, L.L., Gerrard, J., Makris, L., Kane, R.L., Cooper, S., Dunham, T. and Zelterman, D. (1992) 'Inadequate treatment of depressed nursing home elderly', *Journal of the American Geriatric Society*, Vol. 40, No. 11, pp. 1117–22

Hill, S. and Harries, U. (1993) 'The outcome process: some reflections from research with people in their 60s and 70s', *Critical Public Health*, Vol. 4, pp. 21–8

Hockey, J. and James, A. (1993) G*rowing up and Growing Old: Ageing and Dependency in the Life Course.* London: Sage

Hughes, J., Challis, D., Gill, J. and Stone, S. (1997) 'The eligibility lottery', *Working with Older People,* Vol. 1, No. 3, October, pp. 14–17

Hunt, S.M. and McKenna, S.P. (1993) 'Measuring patients' views of their health', letter, *British Medical Journal*, Vol. 307, p. 125

Isaacs, B. and Neville, Y. (1976) *The Measurement of Need in Old People*. Scottish Health Service Studies, No. 34. Edinburgh: Scottish Home and Health Department

Jenkinson, C. (1997) 'Assessment and evaluation of health and medical care: an introduction and overview', in C. Jenkinson (Ed.) *Assessment and Evaluation of Health and Medical Care*. Buckingham: Open University Press

Jenkinson, C., Coulter, A. and Wright, L. (1993) 'Short-form 36 (SF-36) health survey questionnaire: normative data for adults of working age', *British Medical Journal*, Vol. 306, pp. 1437–40

Jerrome, D. (1990) 'Intimate relationships', in J. Bond and P. Coleman (Eds) *Ageing in Society: an Introduction to Social Gerontology*. London: Sage

Jordan, K. (1994a) 'Improving the SF-36 for use with the elderly population', unpublished paper, Centre for Health Planning and Management, University of Keele

Jordan, K. (1994b) 'Results of a health survey of people aged 65 and over in Redbridge and Waltham Forest', unpublished paper, Centre for Health Planning and Management, University of Keele

Katona, C. (1994) *Depression in Old Age*. London: John Wiley and Sons

Katz, S. (1983) 'Assessing self-maintenance: activities of daily living, mobility and instrumental activities of daily living', *Journal of the American Geriatric Society,* Vol. 31, pp. 721–7

Kemper, P. (1992) 'The use of formal and informal home care by the disabled elderly', *Health Services Research,* Vol. 27, No. 4, pp. 421–51. Reprint, AHCPR Pub. No 93–0004

Kendig, H.L. (Ed.) (1986) *Ageing and Families: a Social Networks Perspective*. Sydney: Allen & Unwin

Koch, T. and Webb, C. (1996) 'The biomedical construction of ageing: implications for nursing care of older people', *Journal of Advanced Nursing*, Vol. 23, No. 5, May, pp. 954–9

Lewis, J. and Meredith, B. (1989) 'Contested territory in informal care', in M. Jeffreys (Ed.) *Growing Old in the Twentieth Century*. London: Routledge

Liu, K. and Cornelius, E. (1991) 'Activities of daily living and eligibility for home care', in D. Rowland and B. Lyon (Eds) *Financing Home Care, Improving Protection for Disabled Elderly People*. London: John Hopkins University Press

Lubben, J.E. (1988) 'Assessing social networks among elderly populations', *Family and Community Health*, Vol. 11, pp. 42–52

Mayer, J.E. and Timms, N. (1970) *The Client Speaks: Working Class Impressions of Casework*. London: Routledge and Kegan Paul

Mor-Barak, M.E. and Miller, L.S. (1991) 'A longitudinal study of the causal relationship between social networks and health of the poor frail elderly', *Journal of Applied Gerontology,* Vol. 10, pp. 293–310

Morris, J.N., Hawes, C., Murphy, K. and Nonemaker, S. (1995) *Long-term Care Resident Assessment Instrument User's Manual – Version 2.0.* Baltimore, MD: Health Care Financing Administration

Morris, J.N., Hawes, C., Fries, B.E., Phillips, C.D., Mor, V., Katz, S., Murphy, K., Drugovich, M.L. and Friedlob, A.S. (1990) 'Designing the national resident assessment instrument for nursing homes', *The Gerontologist,* Vol. 30, pp. 293–307

New Zealand Ministry of Health (NZMH) (1994) *Standards for Needs Assessment for People with Disabilities.* Wellington: Ministry of Health

Nolan, M. and Caldock, K. (1996) 'Assessment: identifying barriers to good practice', *Health and Social Care in the Community*, Vol. 2, pp. 77–85

O'Boyle, C.A., McGee, H. and Joyce, C.R.B. (1994) 'Quality of life: assessing the individual', in R. Fitzpatrick (Ed.) *Advances in Medical Sociology.* Greenwich, CT: JAI Press

Office of Population Censuses and Surveys (OPCS) (1991) *General Household Survey 1991*. London: HMSO

Qureshi, H. and Walker, A. (1989) *The Caring Relationship: Elderly People and their Families*. London: Macmillan

Rees, S. (1978) *Social Work Face to Face: Clients and Social Workers' Perceptions of the Content and Outcomes of their Meetings*. London: Edward Arnold

Rook, K.S. (1987) 'Reciprocity of social exchange and social satisfaction among older women', *Journal of Personality and Social Psychology*, Vol. 52, pp. 145–54

Rose, H. and Bruce, E. (1995) 'Gender and social networks in later life', in S. Arber and J. Ginn (Eds) *Connecting Gender and Ageing.* Buckingham: Open University Press

Sarason, I., Levine, H. and Basham, R. (1983) 'Assessing social support: the social support questionnaire', *Journal of Personality and Social Psychology*, Vol. 44, pp. 127–39

Scott, A. and Wenger, G.C. (1995) 'Gender and social networks in later life', in S. Arber and J. Gin (Eds) *Connecting Gender and Ageing.* Buckingham: Open University Press

Seymour, S. (1994) 'Carer or spouse? The self-identification of informal carers in marriage', unpublished paper presented at the 26th Annual Conference of the British Sociological Association Medical Sociology Group

Sidell, M. (1992) 'The relationship of elderly widows to their doctors', in J. George and S. Ebrahim (Eds) *Health Care for Older Women*. Oxford: Oxford University Press

Sidell, M. (1993) 'Health issues and the older woman', in M. Bernard and K. Meade (Eds) *Women Come of Age: Perspectives on the Lives of Older Women*. London: Edward Arnold

Siddell, M. (1995) *Health in Old Age: Myth, Mystery and Management*. Buckingham: Open University Press

Spector, W.D. and Kemper, P. (1994) 'Disability and cognitive impairment criteria: targeting those who need the most home care', *The Gerontologist,* Vol. 34, No. 5, pp. 640–51

Stewart, A.L., Hays, R.D. and Ware, J.E. (1988) 'The MOS short-form general health survey: reliability and validity in a patient population', *Medical Care*, Vol. 26, No. 7, pp. 724–35

Stewart, K., Challis, D., Carpenter, I. and Dickinson, E. (1999) 'Assessment approaches for older people receiving social care: content and coverage', *International Journal of Geriatric Psychiatry,* Vol. 14, No. 2, pp. 147–56

Stewart, M.J. (1993) *Integrating Social Support in Nursing*. Newbury Park, CA: Sage

Tilston, J. and Williams, J. (1992) '"Everyone wants to go to heaven, but no one wants to die." Screening women over 75 – a health promotion approach', in J. George and S. Ebrahim (Eds) *Health Care for Older Women*. Oxford: Oxford University Press

Webb, C. (1992) 'The health of single never-married women in old age', *Journal of Advances in Health and Nursing Care*, Vol. 1, No. 6, pp. 3–29

Webb, C. and Cordingley, L. (1999) 'Expressing sexuality', in S.J. Redfern and F. Ross (Eds) *Nursing Elderly People,* (3rd edition). Edinburgh: Churchill Livingstone

Weinberger, M., Hiner, S.L. and Tierney, W.M. (1987) 'Assessing social support in elderly adults', *Social Science and Medicine*, Vol. 25, No. 9, pp. 1049–55

Weinberger, M., Nagle, B., Hanlon, J.T., Samsa, G.P., Landsman, P.B. *et al.* (1994) 'Assessing health related quality of life in elderly patients: telephone versus face to face administration', *Journal of the American Geriatric Society*, Vol. 42, No. 12, pp. 1295–9

Wenger, G.C. (1986) 'What do dependency measures measure?: challenging assumptions', in C. Philipson, M. Bernard and P. Strang (Eds) *Dependency and Interdependency in Old Age*. London: Croom Helm

Wenger, G.C. (1987) 'Dependency, interdependence and reciprocity after eighty', *Journal of Ageing Studies*, Vol. 1, No. 4, pp. 355–77

Wenger, G.C. (1988) *Old People's Health and Experience of the Caring Services: Accounts from Rural Communities in North Wales*. Liverpool: Liverpool University Press

Wenger, G.C. (1989) 'Support networks in old age: constructing a typology', in M. Jeffreys (Ed.) *Growing Old in the Twentieth Century*. London: Routledge

Wenger, G.C. (1990) 'The special role of friends and neighbours', *Journal of Ageing Studies*, Vol. 4, No. 2, pp. 149–69

Wenger, G.C. (1993) 'The formation of social networks: self help, mutual aid, and old people in contemporary Britain', *Journal of Ageing Studies*, Vol. 7, No. 1, pp. 25–40

Whelan, C. (1993) 'The role of social support in mediating the psychological consequences of economic stress', *Sociology of Health and Illness*, Vol. 15, pp. 86–101

Wild, S. and McKeigue, P. (1997) 'Cross sectional analysis of mortality by country of birth in England and Wales 1970–92', *British Medical Journal*, Vol. 314, pp. 705–10

Wilkin, D., Hallam, L. and Doggett, A.M. (1992) *Measure of Need and Outcome for Primary Health Care*. Oxford: Oxford Medical Publications

Woolstone, S. and Ivings, D. (1994) 'Independent living groups', *Health Visitor*, Vol. 67, pp. 267–8

Zarb, G. (1993) 'Ageing with a disability', in J. Johnson and R. Slater (Eds) *Ageing and Later Life*. London: Sage

Ziebland, S. (1994) 'Measuring changes in health status', in C. Jenkinson (Ed.) *Social Research Today: 3. Measuring Health and Medical Outcomes*. London: UCL Press

Ziebland, S., Fitzpatrick, R. and Jenkinson, C. (1993) 'Tacit models of disability underlying health status instruments', *Social Science and Medicine*, Vol. 37, No. 1, pp. 69–75