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SUMMARY

Introduction

This report presents a review of research literature relating to the range and quality of community care services for older people in Scotland. The review focuses on outcomes for service users and informal carers, identifying and assessing work conducted in this area and outlining any gaps in the evidence base, to inform the development of policy and practice on social care services for older people. Research relating to older people’s perspectives is of particular interest throughout this review. The review was completed in November 2003.

Most of the studies included were conducted in Scotland. Some reference is made to research literature from elsewhere where this has direct relevance to Scottish concerns and fills a gap in the Scottish literature. The highly selective nature of these references was necessitated by the short timescale allowed for the review. Ongoing, or soon to be published, research is referred to where relevant.

Policy in community care has undergone rapid development in the past 5 years. The Joint Future Agenda to promote joint working, the development of National Care Standards and the introduction of free personal care have all had an impact on service provision. In a wider context, ‘Health for All’, ‘Involving People’ and Social Justice are new policy themes which have a bearing on the direction of community care policy.

The research agenda has also changed in significant ways. More research has focused on the perspectives of service users and carers, participatory approaches to research have been influential and, in dementia research in particular, new approaches to seeking users’ views are having an impact on how service users are perceived.

Assessing need in the community

Recent research has demonstrated that needs in terms of people’s own quality of life and expectations may be quite different from needs as catered for by health and social care agencies. Other agencies, and communities themselves, have a role to play. Gaps in community care identified can often be traced to agencies not operating as a network of support and not referring people on.

A Scottish Executive funded audit of research on minority ethnic groups reinforces this general point with a wealth of evidence that older people in minority ethnic groups have poorer access to community care services than others. The audit highlights particular ways in which community care services need to adapt to achieve more equal access.

A study comparing urban and rural networks is particularly helpful in uncovering the social and institutional mechanisms which determine the way local networks operate. At a more individual level, a study of carers draws attention to the importance of individual assessment of carers’ needs as a way of strengthening community supports.

Research involving service users and local communities illustrates how research can play a part in tackling problems of service delivery. In one example, research contributed to a local needs assessment which then led to local improvements in services which were in tune with
the priorities of local people. In the other example the outcome was a direct contribution to professional practice.

**Assessment and care management**

Research on assessment practice is scarce. Analysis of how different professions approach assessment is potentially valuable in the development of multi-disciplinary assessment practice.

There is, equally, little published research on models of joint and integrated working in Scotland. Collaborative and multi-agency research has met with some success in England in actually promoting joint working. In one example, an action plan to improve hospital discharge was the outcome. In another, an integrated care system was developed employing a ‘whole systems’ approach with monitoring and evaluation playing an integral part.

Evidence of unmet need and of inadequate practice continues to emerge from research. Unmet needs for social support in older people with schizophrenia in one NHS Board area were found to be significant and attributable to a failure to provide multi-disciplinary assessment.

A Scotland-wide review of care management has revealed a high degree of variation in the way care management is organised and differing interpretations of what it is. Social Work Departments also appear to offer very different levels of service. 24-hour cover was available in almost all areas but only as an emergency or short term service. Managers from about half of the authorities did not think there was adequate choice for service users.

The policy agenda has focused attention on user satisfaction research. This has progressed in different directions depending on whether the aim is to measure or to improve performance. In English research, using global measures of satisfaction, assessment by a social worker, as opposed to a home care manager, was found to influence satisfaction in a positive way. However, such measures are of limited use for identifying what aspects of a service people find satisfactory or what needs to be changed.

An alternative approach focuses on outcomes of social care for individuals. Three different kinds of outcomes have been distinguished related to: maintenance of quality of life, change, and the process of service delivery. The researchers propose that agreeing outcomes with service users as a stage between assessment and care planning provides care managers with a tool to monitor standards of care.

**Support at home**

A number of studies demonstrate the centrality of service users’ perspectives in achieving good quality services. People’s judgements about specific services are directly related to the effect of the service on the quality of their lives as a whole.

Evidence from research and audit indicates that overall in Scotland there has been a reduction in total home care provision at the expense of people with low level support needs.

There is wide variation in satisfaction with services both from service users and home care workers but also a lack of evidence about what contributes to this variation. One source of
service user and carer dissatisfaction identified is the limited use of care management to monitor and review needs once services have been allocated. The effect of factors such as management practices, service models, labour supply and training on quality as perceived by service users could usefully be explored.

There is a need for more research to be published examining joint services and the lessons to be learned from different models of integration. A national survey of waiting times for adaptations and equipment identified an association between the extent of joint arrangements and lower waiting times.

Studies of community-based palliative care focus on the input of nurses and medical staff and tell us that a high proportion of palliative patients in one NHS area are older people with diagnoses other than cancer.

Innovation in housing and support through the use of telecare has created a new area of interest for researchers. Ongoing evaluation of telecare projects is identifying a generally positive response for staff and service users.

A recurring theme is the problem of poor or inconsistent management information. This compounds the inevitable difficulties for researchers caused by local authorities employing different service configurations and different interpretations of national policy and guidance in their areas.

**Long-term care**

A substantial amount of research on care homes focuses on quality of life for residents, research which has helped to formulate the principles and standards embodied in the National Care Standards. The role of care staff and the relationship between job satisfaction and quality of care remains a neglected area which has obvious relevance for management, training and implementing the required standards of care.

More research is also needed to examine access to health care for care home residents as an issue of social justice. Studies of physiotherapy and palliative care address some important aspects of health care for frail older people. These studies draw attention to the risks of nursing staff in care homes being isolated from information current in primary care teams, and of ageist attitudes influencing access to specialist services for care home residents.

Offering more intensive support in a range of settings is one alternative to the care home model of service. Experience in Denmark and the Netherlands shows the potential for moving towards a person-centred approach to residential care by separating the care plan from the accommodation.

A study of an advocacy service for care home residents found that demand for and understanding of the service could not be taken for granted and that public promotion was essential to ensure take-up. The evaluation also found that longer term involvement by advocates with their partners was needed than had originally been envisaged by the project.

UK wide research on people admitted to care homes on a self-funding basis revealed that they had received relatively less in the way of support services prior to admission than
publicly funded people. The findings suggest that there is unmet need for support at home offering social contact and interest as opposed to intensive personal care.

**Dementia care**

There now exists in Scotland an active network of researchers applying and extending new research methods which focus on ‘hearing the voice’ of the person with dementia. This network is part of a wider international network of researchers whose work is closely linked to innovation in practice. The enthusiasm and commitment of research in this field is distinctive and has generated methods and approaches applicable beyond the field of dementia care.

Dementia research has demonstrated that, given motivation and appropriate training, researchers and others can communicate meaningfully with people and include them in research. One study found that by encouraging non-verbal interaction between carers and people with dementia, more people with dementia were included socially in a group.

There are cultural differences in how dementia is perceived and therefore person-centred approaches and services are the key to understanding and meeting the needs of people with dementia from different ethnic groups.

The main benefit of day care as perceived by unpaid carers is respite for themselves. However by including the perspectives of the service users themselves, research has been able to reveal the therapeutic value of the service for people with dementia.

Research on the potential for people with learning disabilities and dementia to exercise choice and control emphasises the importance of staff attitudes and the need to allow time and space for people to make their choices.

**Conclusions: Key points**

- Research could contribute more to a Scotland-wide view of provision for older people if better use were made of existing data sources, including national surveys and information collected by the Scottish Executive for monitoring purposes.
- Action research and other participatory approaches bring service users’ perspectives to the heart of the service development process. There is scope for more collaborative research and development work in Scotland and better dissemination about successful projects.
- Active collaboration between researchers and practitioners has produced a wealth of new methods and insights which allow people with dementia to be included in discussions about their care, something which was unheard of ten years ago. Health and social service research has a great deal to learn from dementia research about how to ‘hear the voice’ of service users and carers.
- We know more now than five years ago about the experience which older people from minority ethnic groups have of community care. More research is needed involving
people from a wide range of ethnic groups and parts of Scotland to help to overcome the ignorance and prejudice which stand in the way of more equitable service provision.

- Social justice requires all older people to have similar access to basic health and social care whether they live at home or in a care home. There is some evidence that care home residents may be isolated from particular health and other services. More research is needed, based on large representative samples, to establish the extent of such inequity and to inform solutions.

- The characteristics of the workforce who provide basic care is a neglected area in community care research. Raising standards depends on the recruitment and retention of staff who can be trained and motivated to provide person-centred care. There is currently very little evidence as to whether this is achievable.
1 INTRODUCTION

AIMS AND OBJECTIVES

1.1 This report presents a review of research literature relating to the range and quality of community care services for older people in Scotland. The review focused on outcomes for service users and informal carers, identifying and assessing work conducted in this area and outlining any gaps in the evidence base to inform the development of policy and practice on social care services for older people. Research relating to older people’s perspectives is of particular interest throughout this review. The review was completed in November 2003.

1.2 The review set out to identify evidence of differences in service use and availability with respect to geographical location, age, gender or ethnicity; and differences in service use and availability experienced by groups of older people with distinct needs.

1.3 While most of the studies included were conducted in Scotland, some reference is made to research literature from other parts of the UK and abroad where this has direct relevance to Scottish concerns and fills a gap in the Scottish literature. The highly selective nature of these references was necessitated by the short timescale allowed for the review. Other recent and ongoing literature reviews of a more specialist nature are referred to which will provide supplementary information particularly in relation to models of good practice.

1.4 The review was commissioned by the Scottish Executive in July 2003 and completed in August and September. It was limited to completed research which has been published and ongoing, uncompleted research.

Sources

1.5 The main resources for the literature searches have been specialist libraries and electronic databases. The specialist libraries used include those of Age Concern Scotland, the Dementia Services Development Centre at Stirling University, and the Centre for Policy on Ageing (CPA) in London which runs AgeInfo. AgeInfo offers a bibliographic database of over 40,000 books, articles and reports from the CPA’s specialist collection on Social Gerontology. A list of electronic databases and websites used in the search is at Annex 1. Ongoing and recent research, not yet published, has been identified through internet searches and personal contact.

POLICY CONTEXT

1.6 Since the late 1990s the language of ‘efficiency and effectiveness’ which dominated policy discourse has been replaced with a less managerial vocabulary. Where community care intervention was to be ‘needs-led’ in the earlier discourse, the current term is ‘person-centred’. ‘Outcomes’ measured in terms of assessments completed and care packages arranged are no longer viewed as appropriate performance indicators. The NHS and Community Care Act (1993) urged local authorities to consult people in their communities and to involve individuals in decisions about their care. Ten years later, the active participation of service users and carers is taken for granted by national and local agencies and service user-led organisations have multiplied.

1.7 Community care policy in Scotland has continued to pursue the aim of supporting people in their own homes. Additional resources have been allocated to local authorities to
provide intensive home care packages, and ‘intensive care management’ is advocated as a means of targeting care management resources on the most complex cases.

1.8 During the period covered by the review, principles and standards for good quality care have been drawn up by the National Care Standards Committee in consultation with a wide range of stakeholders including people who use services. In a new legislative framework set out in the Regulation of Care (Scotland) Act 2001 the Care Commission now has responsibility for establishing registration and inspection systems so that standards can be monitored and maintained.

1.9 Joint planning and delivery of services, with particular attention to health and social work services, has for some years now been the long-term focus of community care policy. In Scotland, the Joint Future Agenda (Scottish Executive 2000a, 2000b) sets out a programme for the development of better integrated and more coherent community care services. The first stage of the programme is the implementation of single shared assessment.

1.10 The report of the Expert Group on Older People (Scottish Executive 2002a) demonstrates the strategic importance of the joint agenda in its comprehensive coverage of the care needs of older people. In recommendations for tackling problems in the system - such as unmet need for rehabilitation, delayed discharge, inappropriate hospital admission and inadequate community supports - this report highlights time and time again the necessity for multi-agency and multidisciplinary solutions.

Social Justice

1.11 Social justice and equity are generic Scottish Executive policy aims. Community care policy aims to address inequalities in availability and delivery of services throughout Scotland and between particular groups of people. Anti-ageism is a dimension of Social Justice and community care has a particular role to play in achieving the aim of increasing the number of older people who enjoy active, independent and healthy lives. More specifically, the Social Justice Annual Report (Scottish Executive 2002b) states that good services which are accessible and effective should be designed to meet people's needs - better public services mean better working between all those involved in planning and providing the service, including people who use them.

Involving service users and carers

1.12 The idea that older people can and should have a role in the development of policy which affects them has received strong endorsement at national and local government levels. It is now common practice to make arrangements for older people to contribute through participation, partnership working, consultation, and information giving.

1.13 Systems for monitoring progress in the Joint Future Agenda are being developed as part of the Joint Performance Information and Assessment Framework (JPIAF). Reflecting the commitment to take account of service users’ perspectives, the JPIAF have commissioned Infusion Cooperative1 to develop research based methods to assess service user and carer satisfaction with single shared assessment. The intention is that the resulting toolkit will enable service users to express their views using a range of communication modes.

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1 Formerly known as Consultation and Involvement Trust Scotland
1.14 Research and statistical analysis is necessary for understanding the implications of age and ageing for policy, and in planning and developing effective and responsive services. In recent years the Scottish Executive has commissioned numerous studies and reviews concerning older people and their need for services which reflect particular policy concerns. The work of the Care Development Group on the introduction of free nursing and personal care in Scotland was informed by a set of specially commissioned research projects. Of particular interest to the current review is a study of attitudes to the provision of free personal care amongst older people using services. The impact of the new policy of free personal and nursing care for older people is likely to be significant but remains unexplored.

RESEARCH CONTEXT

1.15 During the 90s community care research was dominated by interest in the changes brought about by the NHS and Community Care Act. The particular themes were identified in a review of research by Harper (1999) commissioned by the Nuffield Foundation:

- efficiency and effectiveness - the relationship between resources, needs and welfare
- implications of the mixed economy of care and the role of the private sector
- the role of informal carers.

1.16 Whilst the Harper review had a broader remit than the current one, it provides a useful benchmark against which to assess trends in community care research in the years since it was published.

1.17 Having reviewed the existing literature, Harper identified the following important areas where research was needed.

research at the interface of medical and social care
Harper identified limited opportunity and support for inter-disciplinary and inter-professional understanding across the medical/social divide: “not only does the interface between medical and social care become increasingly blurred in later life, but there are several research areas which would greatly benefit from acknowledging the complete spectrum of medical and social aspects to healthy successful ageing”.

research to help understanding the personal strategies and decisions which influence people in their use of services
Harper advocated research and policy which “restores the individual, their family and support network to the centre of the research question”.

housing issues
Whilst there was a significant body of research on housing as an integral part of community care, there had been virtually no research to help our understanding of the extent of, or the reasons for, homelessness - understanding which could contribute to effective interventions.

minority ethnic groups
Harper points out that little is known about the relationship between older people from minority ethnic groups and the health and social care provision appropriate to their needs, nor about the cultural and social context of their specific experiences of ageing.
1.18 The needs of minority ethnic groups including older people was the subject of a literature review commissioned by the Executive’s Development Department and is an important source of information for the current review.

1.19 A recent scoping study presents a wide range of descriptive material about older people in rural areas (Philip et al 2003).

**Service user and care perspectives**

1.20 Pervading much of the research in the social care field was, and is, a concern with developing meaningful measures of outcomes from the perspectives of service users. This concern has produced quite distinct methodological approaches. On the one hand, researchers have developed and tested highly structured instruments for measuring well-being, quality of life, satisfaction etc. These can be used in statistical analysis which aims to account for variation in outcomes in terms of variable inputs (models of care management, care packages, costs etc). On the other hand, exploratory and qualitative research aims at more detailed formulations of good and bad outcomes which can feed into the development of good practice.

1.21 Involving service users in research and seeking their views has become a necessary feature of community care and health service research, not least because service users are asserting their right to be heard. Increasingly, service users and others judge the validity of research on service delivery and organisation by the extent of service user involvement and the methods used for seeking their views.

1.22 The effective organisation and delivery of services depends on service users’ views being heard. Health and social care services involve collaboration between professionals, caregivers and service users. Research which takes account of service users’ views is essential for planning and delivering person-centred services. This view is reflected in the Research Governance Framework for Health and Community Care which specifies, as one of the criteria for good quality research, that -

“Research is pursued with the active involvement of service users and carers including, where appropriate, those from hard to reach groups such as the homeless.”

1.23 Interest in participatory research reflects the more general movement amongst users of health and social services towards greater involvement in decisions which affect their lives. During the 90s this movement was most clearly articulated by organisations of younger disabled people and users of services. More recently, organisations of older service users have become increasingly vocal and involved in local and national consultation and decision making. Researchers and research commissioners pay attention to such developments – a growing body of literature presents a range of approaches to involving service users as research participants.

**Issues of methodology**

1.24 This review focuses on research concerned with the experience and perspectives of older people themselves and their unpaid carers. This reflects current trends in policy and practice towards the promotion of person-centred practice, of participation and empowerment for users and carers, and interest in user satisfaction measures in performance monitoring. The changes in attitudes and expectations which have produced these trends have also been
influential in research: the period covered by this review has been one of intense methodological debate and exploration for researchers in the field of community care.

1.25 These methodological debates have been strongly influenced by the disability movement and the demands from users of services and unpaid carers for more say in the way services are planned and delivered. Issues under discussion include: ethical processes for obtaining informed consent from research participants (Hubbard et al 2001); confidentiality; methods for including in research samples people who need support to help them communicate (Murphy J 1998; Stalker et al 1999a); and participatory approaches (Hanley 2000). In the NHS in England INVOLVE (formerly ‘Consumers in NHS Research’), and in Scotland ‘Involving People’ are committed to disseminating good practice in seeking service users’ and patients’ views in health service research.

1.26 The views of people with dementia in particular have been under-represented in research but recent work discussed later in this review has demonstrated that this is not inevitable. Wilkinson (2002) brings together a wide range of material covering these ethical and methodological issues as they relate to research involving people with dementia.

1.27 Participation in research by research ‘subjects’ can occur at a number of levels. Minimal participation occurs when older people are asked to respond to interviews as research subjects and are provided with feedback. At a slightly higher level of involvement lay people or representatives of organisations of older people may be invited to join advisory groups overseeing research. A much greater degree of participation is evident in research when older people are involved in group discussions/workshops to help formulate research questions and methods, and participate in collection and analysis of data. These innovative research practices share the methods and approaches used in consultation exercises involving service users (Barnes and Bennett 1998).

1.28 Researchers have also borrowed from systems theory when seeking collaborative approaches which aim “to reflect the diversity of the arena of care and to explore systems rather than discrete services”. Appreciative Inquiry is one such approach - a method for exploring positive aspects of the social world with the aim of making systemic improvements (Reed et al 2002).

1.29 Amongst other things, these trends have brought renewed interest in action research in its broad sense of a community-based method used to study social systems with the aim of changing them (Bowling 1997). Fulop et al (2001) characterise action research as an approach rather than a method which is committed to doing research with or for people rather than on them. Action researchers treat participants as partners in research, empowering them by passing on research skills and knowledge to actively bring about change (Hart and Bond 1995). A community development approach is also evident in the ‘rapid appraisal’ method developed by Murray (1999) in primary care. Rapid appraisal, action research and participatory research methods share a common aim of using the process of research to directly bring about change.

1.30 Research commissioners are also influenced by the development of a culture in which service users and carers are increasingly characterised as partners rather than clients. This is reflected in the subject matter and focus of much of the research included in this review. Both researchers and research commissioners, particularly the charitable foundations, when evaluating community care services look for ways to achieve practical outcomes from research. Thus participatory research with service users and carers is not seen
as desirable for its own sake, but as a way of increasing the capacity of service users to exercise choice and control and thereby produce better outcomes in terms of community care (Carter and Beresford 2000; Reed et al 2002).

SCOPE AND STRUCTURE OF THE REVIEW

1.31 The criteria agreed for the inclusion of ‘Scottish’ literature in the review are set out below:

- the research has been published since 1998 - or is ongoing research which has not yet been published;
- all, or a significant part, of the fieldwork for the research was conducted in Scotland;
- the research questions focus on outcomes for service users and/or informal carers;
- the research is not purely descriptive but employs valid quantitative or qualitative methods of analysis.

1.32 The review is divided into sections which relate to aspects of community care services as follows: assessing need in the community; assessment and care management; support at home; long-term care; and dementia care. At the end of each section there is a short summary.

1.33 The final section of the report is a discussion around themes which are common to the research reviewed as a whole. These themes are: gaining a Scotland-wide view; promoting collaboration and new models of joint working; hearing the voice of service users and carers; taking account of minority ethnic groups; exploring issues of equity and ageism; and analysing the effect of workforce issues on quality of care.
2 ASSESSING NEED IN THE COMMUNITY

2.1 This section looks at Scottish research concerned with need for and access to community care, from the perspectives of older people and carers. The first studies discussed explore older people’s perspectives on, and experience of, community care services. Participants in these studies are potential as well as actual users of services. Studies relating to the needs of carers are included as is research on the particular needs and priorities of minority ethnic groups. Also included are studies which take a health promotion standpoint, relating the experience and priorities of local people to the overall goal of improving health and quality of life in the community. The final study discussed compares access to community care in urban and rural areas, basing its analysis on the perspectives of a wide range of provider organisations and carers.

2.2 Taken as a whole, the work described in this section goes some way towards meeting the need identified by Harper (see Introduction) for research to help with understanding the personal strategies and decisions which influence people in their use of services.

OLDER PEOPLE’S PERSPECTIVES

Perceptions of needs and access to support

2.3 As long-stay NHS care contracted and increasing numbers of dependent older people are supported by community care Social Work Departments have increasingly targeted their services on the most dependent older people. The effect of targeting on the support available for the wider population of older people needing less intensive support services is illustrated by research on older people’s perspectives on their needs and the availability of support (MacDonald 1999).

2.4 Using a combination of postal survey and in-depth interviewing, MacDonald’s study estimates the level of self-perceived need for support in the urban population aged 75+ living in their own homes. A representative sample was drawn from GP lists in Glasgow and Edinburgh and a response rate of 65 per cent was achieved for the postal survey - giving a sample of 1022. About one third of respondents felt limited in their ability to perform everyday tasks and 28 per cent felt they lacked social contact. These proportions were significantly higher in the less affluent areas sampled. Although 30 per cent said they used home care or day care services, many of those who appeared to have the highest support needs were not among them.

2.5 A sub-sample of 79 respondents with identified support needs were interviewed. Findings suggested that chance played a large part in whether people received adequate support from primary health care and social services. Knowledge about social work services was very low amongst both clients and non-clients.

2.6 Local networks of community-based groups, neighbours and relatives played an important part both in providing support and in connecting people to statutory services. Older people whose first priority was to maintain their independence placed a high value on the Attendance Allowance (a non means-tested benefit), having a wide choice of social and transport facilities and having access to services such as physiotherapy and chiropody.
2.7 MacDonald’s study draws attention to the gaps between on the one hand, agency’s goals and intentions for delivering community care, and on the other, older people’s personal goals for maintaining their quality of life. It concludes that more consistent and longer term funding for voluntary and community-based facilities, and more open access to advice about services are necessary to support independence and prevent crises which lead to dependence on intensive services.

2.8 A parallel study of South Asian older people (Bowes et al 2000) conducted immediately after MacDonald’s study provided the opportunity for a comparative analysis of the perspectives of older people from majority (i.e. white) and minority (South Asian) ethnic groups. This analysis found that although the two groups had similar needs, their use of services, particularly home care and equipment and adaptations services was much lower in the South Asian sample (Bowes and MacDonald 2000). Other research relevant to the needs of minority ethnic groups is discussed later.

Health promotion

2.9 The Nuffield Centre for Community Care Studies at Glasgow University completed a study in 1998 of health promotion and community care which aimed to assess the potential for collaboration between agencies concerned with health promotion, including Health for All, community care and primary care, with the aim of improving health and well being. The barriers to improved quality of life experienced by service users and carers were explored; professional and policy makers discussed difficulties and opportunities for collaborative working. The researchers conducted focus groups and interviews with a range of stakeholders including 6 groups of older people, one for each of the following groups: active residents of a northern island; Chinese people; frail care home residents; day centre members on low incomes; nursing home residents; and sheltered housing residents.

2.10 The study’s findings are consistent with those of the MacDonald study. The older people in the Nuffield study viewed community care services very much in the context of their own efforts to be independent. For carers, quality of life was linked to both the demands of caring and the difficulties faced in dealing with other care providers. Users and carers could readily identify the kinds of action required to improve their quality of life – even small changes could bring large gains. But their experiences suggested that an understanding of the links between improving quality of life, achieving independence and integrating service delivery were largely missing at the level of policy within agencies. Without a stronger voice, users and carers felt that their needs could be ignored. The report puts forward recommendations for pursuing better quality of life for users and carers at strategic, operational, training and educational levels.

Assessing local needs

2.11 Rapid appraisal is the term used by Murray (1999) to describe a technique for incorporating lay perspectives into research and development, specifically in the assessment of local needs, in primary care research. The method of rapid appraisal involves local people in identifying local health needs and can have much in common with methods used in action research. Information about the neighbourhood is collected from interviews, observation and written sources and used to define local needs.

2.12 In Dumbiedykes, Edinburgh, Murray and other members of the primary care team carried out interviews to collect local information and views (Murray 1994). A joint action
plan was then formulated between residents and local service providers. The top priorities for change which emerged in this plan were not related to the health service but to the bus service, play areas and shopping facilities. A health forum of residents and various professionals who worked in the area was set up and met regularly to pursue the joint action plan.

2.13 Rapid appraisal was judged to be an effective method of facilitating the meeting of local health needs. In subsequent studies it was found that rapid appraisal worked best in small homogeneous communities. It has also been found to be an effective training method both for induction of new members of the primary care team and as a method to teach “community diagnosis” to medical students (Murray 1999). Students were able to learn about and observe social and environmental factors which determine health.

CARERS’ PERSPECTIVES

Support needs of unpaid carers

2.14 The breakdown of informal care is well established as being a critical factor in determining admission to institutional care. A high level of dependency in the person cared for, dementia severity, and care by a non-spouse have been cited as factors which can ‘predict’ institutionalisation (cited in McKee et al 1999). However, evidence from the Dundee Study of Carers and Dementia (McKee et al 1999) suggests that it is the impact of the dependency and dementia on the care giver and their willingness to continue caring which is the crucial factor rather than the characteristics of the cared for person.

2.15 The study examined factors associated with the maintenance and care of older people in the community and with the impact of dementia on family supporters. Two samples of 114 older people with a family carer were included in the study, one group with dementia the other without. Quantitative and qualitative analysis found that carers’ willingness to continue caring was associated with self reported stress and with the way they felt about their relative’s condition. Thus, carers who did not identify any problem with caring for their relative were more likely to continue caring than those who did. The feelings created by the problem (of caring) rather than the problem per se was what led to institutionalisation.

2.16 In discussing the implications for improving the well being of family carers, the Dundee study concluded that a focus on carers’ responses to their situation would help more people to continue caring, provided that was their wish. These findings underline the importance of the separate assessment of carer’s needs in efforts to avoid older people being admitted to care homes against their will.

Involving informal carers in care planning

2.17 Researchers based at Queen Margaret University College used research based methods to develop and validate “guidelines to facilitate the involvement of lay carers in the care planning of the person with dementia in hospital” (Walker et al 1999; Goulbourne et al 2000). The first stage investigated the issue of involvement in a unit providing day, respite and assessment for psycho geriatric patients within a hospital, with the aim of developing guidelines. The design of the study was intended to allow a deep exploration of barriers to involvement already familiar from research literature.
Participants in the study included 20 lay carers, 18 qualified and assistant nursing staff, other members of the multi disciplinary team including doctors, OTs and social workers. Data were gathered from a combination of interviews, focus groups, observation, field notes and formal documentation. The guidelines were based on a thematic analysis of these data.

Given the lack of any agreed set of principles or procedures for nursing staff to follow to ensure that carers had equal opportunities to be involved, involvement was found to depend on the assertiveness of carers themselves and the responsiveness of individual staff. There were four ways that carers could feel involved confirmed by the analysis: information being shared with them; being included in decision making; feeling able to contact someone when needed; feeling that the service responds to their needs. The guidelines were drawn up to help staff work towards fulfilling these objectives (Walker et al 1999).

The guidelines produced were validated by a group of carers in a follow-up exercise. Fifteen carers contributed their views in two separate workshops and a further 4 responded in writing. The guidelines were tested to see if they differentiated sufficiently between carers’ differing circumstances. Carers in community settings stressed the key role of the GP and the need for several key contacts to help with the multitude of needs. The carers found the guidelines relevant to their situation and felt they would be helpful. However they acknowledged the practical difficulties of implementing them, as did the 8 professional workers who attended a dissemination workshop. Amongst their recommendations the researchers call for further dissemination of the guidelines and validation with other client groups and health and social care professionals (Goulbourne et al 2000).

The needs of black and minority ethnic carers of older people and barriers to service provision are the subject of a study by Netto (2001). A sample of 45 carers in Lothian were involved in interviews and focus groups. They included one third of Chinese origin, one third Pakistani and the remainder from a range of origins including Afro-Caribbean. Particularly striking are findings about the lack of suitable respite services, the lack of information and interpreting services and lack of benefits advice.

MINORITY ETHNIC GROUPS

In 2001 the Scottish Executive published an audit of research on minority ethnic issues in Scotland (Netto et al 2001). Section four of the report, concerned with ‘Race and Social Care’, provides a wealth of information drawn from studies of the experiences of particular groups of minority ethnic people, of social work policy and practices, and of the need for culturally sensitive services. Emerging themes from studies involving older people include: high levels of unmet and hidden need; low levels of knowledge of existing services; difficulties in accessing services; low use of home support services; and lack of cultural sensitivity in service provision.

Cultural and demographic change within communities gives rise to new issues for older people. A study of the Jewish community emphasised the importance of planning services which take account of the cultural and religious needs of an ageing community who were increasingly living apart from their family (Samuel and Pearson 1999, cited in Netto et al 2001).

The audit concludes that studies are almost exclusively local or regional in coverage and conducted in the main in Edinburgh or Glasgow. Studies have focused on the Pakistani
or South Asian communities with the result that little is known about older people of Chinese, Afro-Caribbean or other origin. A number of gaps in research are identified: the needs and experiences of older people in residential care; studies which explore and evaluate how the design of existing services can be adapted to take account of particular cultural needs; and studies of the experiences of disabled people in minority ethnic groups.

2.25 In general, research in this area presents evidence of the diversity of minority ethnic groups whilst reporting on their common experience of racial harassment and discrimination in Scotland, and a sense of exclusion from mainstream services (Netto et al 2001).

2.26 Bowes and Dar (2000) in a study which employed parallel methods to that of MacDonald (1999) discussed earlier, interviewed 102 South Asian older people about their experiences of seeking and finding care and support. In-depth follow up interviews were conducted with a sub-sample of 30 older people and with 10 family carers. The researchers found that housing problems were very common, people did not have adaptations or equipment to aid mobility and applications for rehousing had been unsuccessful. Specialist day care services provided for their ethnic communities were virtually the only social service used by participants. Although these services were valued, referral systems from community groups and from primary care to social work departments were particularly ineffective for minority ethnic older people, resulting in unmet need for home care, adaptations and equipment.

2.27 Bowes and Dar’s findings echo a common theme which Netto et al (2001) found in a range of studies about minority ethnic groups’ access to specific health services. Services evaluated included several of particular importance for older people: an arthritis project (Munro, 1996, 1999); podiatry services (Ahmed et al, 1995); and respite services for carers of older people (Netto, 1998). Lack of knowledge of services and of screening procedures, difficulty in communicating with GPs and greater inhibition about discussing certain aspects of health are all identified as contributing to lower referral rates and inadequate health care as a result. Particular issues for people from minority ethnic groups who have dementia are discussed later in Part 6.

**COMPARING URBAN AND RURAL COMMUNITY CARE NETWORKS**

2.28 Milligan’s (2001) research is concerned with care networks and how they are differentially influenced in rural and urban areas by government restructuring. The conceptual framework for her research, described in some detail, has very immediate relevance to the issues of policy implementation faced in community care.

2.29 Between the ‘micro-level’ of the individual exchange between carer and service user and the ‘macro-level’ of national legislation and policy guidance there exist various agencies which translate policy into a social programme at the ‘meso’ or local level. The framework is represented as a network in which local structures and institutional practices, together with the everyday routines of experienced practitioners in statutory, private, voluntary and informal sectors, are activated to produce community care outcomes.

2.30 The value of this conceptual framework was explored by Milligan in a study carried out in Dumfries and Galloway and in Glasgow in 1996-1998 in which she examines the experiences of providers of care to frail older people and how they can influence and be influenced by the physical and social environment in which change occurs. The Community
Care Act and the restructuring of local government were identified as the macro-level changes taking effect at that time.

2.31 The study employs a longitudinal in-depth approach suited to the aim of observing interactions and the effects of change. Research methods included: a postal survey of voluntary sector organisations followed by serial interviewing of a sample of respondents (12 in Dumfries and Galloway and 28 in Glasgow); focus groups with informal carers followed by serial interviewing and diary keeping with a sample of 12; a postal survey of private sector providers; and in-depth interviews with key people in statutory health, social work and housing agencies.

2.32 The findings of the research draw attention to specific aspects of rural disadvantage which have a direct impact on the range and quality of services available.

i. Urban areas experience economies of scale in service delivery because of the larger concentrations both of people and of deprivation. Transport costs are higher in rural areas but the scarcity of transport also reduces access and choice.

ii. Methods of allocating government funding mean that relatively small pockets of deprivation – and the higher costs of service delivery - are overlooked. This was found to have a disproportionate impact on funds available for the voluntary sector in rural areas. Fewer voluntary organisations operating in Dumfries and Galloway compared with Glasgow means increased reliance on informal care.

iii. Access to Urban Programme funding provides opportunities to develop innovative and flexible services independently of the local authority.

iv. The more dispersed and ageing population in rural areas means a restricted supply of volunteers and informal carers.

2.33 The strength of the network and its ability to support older people was also affected by political and ideological differences at local government level and by whether or not local authority and NHS Board boundaries were coterminous. In Dumfries and Galloway, coterminosity facilitated joint planning and working (Milligan 2001).
SUMMARY

2.34 Two distinct themes emerge from the research discussed in this section. The first theme, emerging from research by MacDonald (1999) and Nuffield (1998), concerns the gap between the support people actually need and what is on offer. Needs in terms of people’s own quality of life and expectations may be quite different from needs as catered for by health and social care agencies. Other agencies, and communities themselves, have a role to play. Gaps in community care identified can often be traced to agencies not operating as a network of support and not referring people on.

2.35 Netto et al’s (2001) audit of research on minority ethnic groups reinforces this general point. It provides some evidence that older people in minority ethnic groups have poorer access to community care services than others and highlights particular ways in which community care services need to adapt to achieve more equal access.

2.36 Milligan’s (2001) comparison of urban and rural networks is particularly helpful in uncovering the social and institutional mechanisms which determine the way local networks operate. At a more individual level, the Dundee carer study draws attention to the importance of individual assessment of carers’ needs as a way of strengthening community supports.

2.37 The second theme of involving people in service development is illustrated in very different ways in two of the studies discussed. In the Dumbiedykes study (Murray 1999) research contributed to a local needs assessment which led to local improvements in services in tune with the priorities of local people. In the carer guidelines research (Walker et al 1999) the outcome was a direct contribution to professional practice.

2.38 This theme of involving service users and carers in research in order to achieve practical outcomes is a recurring one for this review and is discussed in the concluding section of the report.
3 ASSESSMENT AND CARE MANAGEMENT

3.1 Assessment and care management are the practices which frame the delivery of community care, and research which helps in the development of joint or integrated practice is of particular interest for this review. Research on hospital discharge is also included in this section on the grounds that the practices involved are, or should be, closely related to assessment and care management as practiced in the community. A brief summary of the English programme of research on outcomes of social care is included because of its potential value for care management practice in Scotland.

ASSESSMENT PRACTICE

3.2 It is surprising given recent interest in single shared assessment procedures that there appears to be a dearth of Scottish research on assessment techniques and how these differ between the professions. Bryans’ (2000) study of district nursing assessment practice is therefore of some interest for the current review.

3.3 In a case study of good practice based on a fictitious scenario, Bryans describes the knowledge and skills involved in initial patient assessment by district nurses. The case study presents an illustration of the distinct qualities of good assessment practice. These include “fluent and appropriate use of a practitioner's knowledge base resulting in rapid and accurate recognition of the patient's needs”. The practice described is thoroughly patient-focused: “The overall approach involved a fine balance between the patient's agenda and that of the assessor interweaving the nurse-initiated issues while following the patient's cues.” The nurse had the explicit aim of getting the patient to identify her own problems. Intensive and thorough questioning about all aspects of the patient's condition was avoided so as not to “put the patient off”. This research is highly relevant to the development of single shared assessment in that it illuminates the approach and values which nursing bring to the assessment task.

3.4 Assessment and early diagnosis of dementia is clearly essential to facilitate appropriate treatment and support for people with dementia. An ongoing study is focusing on the memory clinic model in order to understand the future needs of the population and how these might best be met through specialist practice. The most common response to the assessment needs of people with dementia are memory clinics which began to appear in the early 1980s and are now common in UK, US and Europe. A survey of memory clinics across the UK (Wright and Lindesay 1995) described the activities of 20 memory clinics (including 3 in Scotland) and found that, despite broadly similar aims and general operating characteristics, clinics varied considerably in the numbers of people assessed and diagnosed.

Needs assessment and unmet need – older people with schizophrenia

3.5 McNulty et al (2003) present what appears to be an isolated example of research addressing the community care needs of older people with functional mental illness. Using a structured approach to data collection, their study measures the extent of unmet need in a sample of elderly people with schizophrenia in North Lanarkshire. The sample included 10 people in long stay hospital; 11 placed in private nursing homes (under a partnership agreement whereby NHS consultants remain the responsible medical officers); and 37 living

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2 Wilkinson H, Investigation into the Current Volume and Models of Specialist Diagnostic and Assessment Service Provision in Scotland. Funded by Alzheimers Scotland Action on Dementia 2002-3.
in their own homes or with relatives. Problems and needs were assessed in relation to a range of clinical and social areas of functioning. A problem was defined as 'cardinal' if one or more of the following applied in relation to the particular objective problem: the patient was willing to accept help; the caregivers were experiencing severe anxiety, annoyance or inconvenience; the health and safety of the patient or others were put at risk. Needs were then identified as cardinal problems if a suitable intervention existed but had not been given a recent adequate trial.

3.6 Results from the comparison of clinical symptoms showed that people in the community had lower scores on average than those in hospital or partnership homes, with the exception of depression/anxiety for which average scores in the community were significantly higher. In 27 of the 58 cases (48 per cent) there was no social need identified. From 69 cardinal problems identified in areas of social functioning (domestic skills, finance and welfare, transport and amenities, social life, hygiene and dressing) a total of 23 needs were identified. In addition 14 needs related to inappropriate accommodation. Hospital inpatients had considerably more social care needs on average than others in the sample. Those in the partnership homes had the least.

3.7 For the 37 people living in the community, total needs (both social and clinical) were higher for the 17 receiving care from the Community Mental Health Team compared with the 20 who were not. However the authors note the substantial number of needs in those not receiving multi-disciplinary mental health care and that little was currently being done to assist such patients in spite of their having more than 2 cardinal problems each. They conclude that systematic needs assessment is the basis for improving levels of care - a process undermined by shortages of professional staff and local lack of funding in Lanarkshire.

JOINT WORKING MODELS

3.8 Integrated health and social care teams offering intensive support have been in existence in parts of Scotland for some time but joint health and social care teams offering mainstream services are at an early stage of development. Independent evaluations of work in this area which have been published are hard to find. An English evaluation of two integrated teams in a rural area concluded that the features of integration adopted, such as co-location, were insufficient in themselves to produce better outcomes for older people. The authors conclude that more evidence is needed to support the claim that integration is of benefit, but that evaluation in itself is impractical so long as health and social care agencies maintain separate and incompatible information systems. “If the Department of Health wishes to move from benefits in process to benefits to users, then it seems as if it will have to win over the hearts and minds of not only the front-line staff, but the senior managers and politicians charged with making this happen.” (Brown et al 2003) The difficulties and expense of conducting comparative research to demonstrate the efficacy of integration are discussed in Levin et al (2002).

3.9 The integrated care model discussed by Foote and Stanners (2002) exemplifies a systems approach to care for older people in which ongoing evaluation is an essential element. Key characteristics of the Elderly Persons Integrated Care System (EPICS) in Marlow, South Buckinghamshire include: the older people are involved in running the service; the response to assessed need is multi-disciplinary without the need for referral from one agency to another; information and 24-hour telephone contact is available from the service base. The evaluation of the original EPICS project (a number of other projects have
adopted the same model) shows that the approach was successful in reducing the average length of stay in hospital by 10 days.

3.10 Satisfaction with the EPICS service was monitored through interviews with clients and a survey of referrers. Client satisfaction interviews were conducted with every 16th person referred by a team of volunteers. An example is given of an improvement to the service made arising from these interviews: the contact number for the project was distributed to all older residents in the area in the form of a label to stick on their telephone. The survey of actual and potential professional referrers recorded that 87 per cent were very satisfied with the service. The reasons given were: the convenience and appropriateness of the service, the immediacy of response, the local community base and the lack of any similar alternative (Foote and Stanners 2002)

CARE MANAGEMENT

3.11 Stalker and Campbell (2002) reviewed how local authorities in Scotland were using care management to sustain people at home in a study commissioned by the Scottish Executive. They conducted a Scotland-wide survey to obtain the views of service managers and care managers about policy and practice in each council area. Four of the 5 detailed case studies of care management practice carried out incorporated a small number of visits to service users or carers.

3.12 The Scotland-wide survey revealed a high degree of variation in the way that care management was perceived, organised and delivered. Most striking was the apparent lack of a shared understanding of the meaning of the term ‘care management’. ‘Single shared assessment’, currently the main vehicle by which the Executive seeks to promote joint working, was also found to be susceptible to varied interpretation. These findings illustrate the difficulty of monitoring the implementation of new policies in social care.

3.13 The lack of a shared understanding of what ‘care management’ meant was also the case in 1994 when a study of how care management was being implemented in Scotland found widely different interpretations both between and within the four local authorities sampled (Petch et al 1996). The two studies were concerned with broadly the same issues: the nature and practice of care management; the characteristics of care managed cases; the extent to which budgets are devolved; creativity in care planning; and training needs for care managers. However in the commissioning of the later review there was apparently no clear intention to track progress on the basis of the earlier study.

3.14 Case studies were selected purposively in Stalker and Campbell’s study for their good practice features including multidisciplinary working, effective screening, effective single shared assessment tools, budgets devolved to care manager level and a high level of user involvement. The study found that predominantly rural authorities were more likely than urban to have adopted creative care management practices and the report suggests that this may not be accidental. Smaller authorities lend themselves to closer working relationships between staff at different levels and in different agencies.

3.15 The study provides some evidence, based on the reports of service and care managers, of the ability of local authorities to sustain people with complex or intensive support needs at home. More detailed data produced by Curtice et al’s (2002) study of intensive care is discussed in part 4 of this review.
3.16 In 15 authorities 24-hour care was an option but only on a short term basis or when extra funding was available, and 17 authorities could offer 24-hour emergency cover. In 6 authorities it was said that 24-hour cover was not available at all. Of the 32 care managers interviewed, 19 said that it was possible to find creative ways to support people with rapidly changing needs in their own homes, 3 said it was not easy and 10 said it was difficult. The difficulties commonly mentioned were: lack of resources, budgets not devolved to care managers, inflexible services, lack of transport, lack of direct access for care managers to providers, restrictive local authority guidelines and protocols and waiting lists for services. Some examples are given of methods and resources which helped creativity. Older people were less likely to be offered long-term intensive support than younger disabled people - the high cost of a care package could be the trigger for a nursing home option.

3.17 About half the care managers interviewed did not think there was enough good quality provision locally to give users a choice. Choice for older people was usually limited to a choice between various care homes.

3.18 Findings from a study of care management arrangements in England (Weiner et al 2002) are not dissimilar to those from Scotland: there was considerable variation in care management arrangements; few authorities had differentiated levels of care management; and little evidence emerged of health service staff acting as care managers.

3.19 Service users’ views played a central part in another English study which examined experiences of care management at the operational level (Ware et al 2003). Findings are based on analysis of case files as well as in-depth interviews with 55 users, 37 carers and 28 care managers in 7 local authorities. The research found a pronounced emphasis on procedure based practice to the detriment of the fostering of personal relationships with users and carers. Fragmentation of the assessment and care management process could lead to discontinuities in the provision of care.

User satisfaction with assessment and care management

3.20 Ongoing research commissioned by the Scottish Executive (see Introduction) aims to develop reliable methods, based on research and on existing good practice, to assess service user and carer satisfaction with single shared assessment. The intention is that the resulting toolkit will enable service users across Scotland to express their views using a range of communication modes. Results are expected in late 2004.

3.21 The Department of Health requirement for user and carer satisfaction surveys in England and Wales has prompted considerable debate about approaches to measuring user satisfaction. One approach has been explored using data from a major study entitled ‘Evaluating Community Care of Elderly People’ (the ECCEP study) (Chesterman et al 2001). Satisfaction was measured using three global questions in interviews with a sample of 418 community-based service users and care managers at time 1, and 224 surviving users 6 months later. The first two questions asked about satisfaction with the assessment (time 1) and with services received (time 2) using a 5 point scale of satisfaction. People with severe cognitive impairment were excluded from this data collection reducing the sample to 326 at time 1 and 206 at time 2. The third question (time 2) asked whether the experience of social services had been ‘favourable’, ‘mixed’ or ‘unfavourable’. The analysis investigated statistical associations between user satisfaction with services, general life satisfaction and case characteristics relating to the service user, resource inputs and local authority.
Overall, the researchers concluded that the support provided was not adequately addressing user needs. Being frequently lonely and having arthritis or rheumatism reduced satisfaction at time 2. However, one striking result of the analysis is that users whose care manager was a qualified social worker were more satisfied at time 2 than users whose care manager had been trained as a home help organiser. Furthermore, the greater the number of social worker hours invested in setting up services, the greater the satisfaction at time 2 with the experience of social services.

The limitations of this method of measuring service user satisfaction are acknowledged by the authors. Expressions of satisfaction may be as much a reflection of user and carer circumstances and characteristics as they are of social care interventions. Interest in user satisfaction surveys is partly a reflection of the general concern of policy makers to ensure Best Value for service users and carers. The idea of a user satisfaction ‘measure’ for use as a performance indicator has an obvious attraction for managers seeking streamlined quality assurance mechanisms. Whilst the method described by Chesterman et al has some value as a research tool for exploring associations between satisfaction and other characteristics of cases, it may be of limited value to agencies wanting to know how to improve their care management arrangements.

Qureshi and Rowlands (forthcoming) outline an alternative to the method proposed by Chesterman et al, one which is designed to address issues which are meaningful and relevant to service users and using cognitive testing as a method of validation. They also present a clear exposition of the different functions of user satisfaction surveys from an organisational viewpoint. They highlight the tension between the goals of performance measurement and performance improvement and argue that a different approach is required depending on which goal is pursued.

Research on outcomes of social care

In 2001 the Social Policy Research Unit (SPRU) at York University completed a five year Department of Health funded research programme on outcomes of social care. The work aimed to develop and test practical ways for agencies to collect and use information about outcomes of services for three groups of people: older people, carers and disabled adults of working age. Methods for outcomes focused practice developed by SPRU have been adapted for use by a number of Social Services Departments in England including Bradford and Derbyshire.

The SPRU research is valuable because of its focus on changing practice: the development of tools and methods for measuring outcomes was treated as a stepping stone to the creation of what they call “… a complete feedback loop in which relevant and useful information is collected, correctly interpreted and acted on”. (Qureshi et al 1998). The outcomes under discussion were ‘final outcomes’ i.e. the ultimate effect of an intervention on the user, rather than ‘intermediate outcomes’ such as delivery of a particular service.

The first stage of the programme explored the views of service users, carers and staff in one social services department to identify what outcomes were relevant. Older people, for example, were consulted using group and individual interviews, with groups meeting on more than one occasion to allow people time to form considered opinions on the issues. Amongst the older people consulted were people with dementia, users of social day care services and people from minority ethnic groups.
3.28 The consultation process provided the basis for a practical framework for understanding outcomes which distinguished three different kinds of outcomes:

- **maintenance** of quality of life in terms of, for example, acceptable standards of comfort, social contact, activity and control over daily life;

- **change**, for example, improving confidence, reducing risk, increased mobility and recovery of skills;

- **impacts of service process**, for example, feeling valued and respected, services fitting in with personal preferences and other sources of help (Qureshi et al 1998).

3.29 Unlike change outcomes, where measurement is required at more than one point in time, maintenance and service process outcomes are assessed by comparing them with a defined standard. The researchers argue that, given that deteriorating health is a common characteristic of older and disabled people requiring social care, judging social care activity solely on evidence of improvement in the individual’s functioning would be unhelpful (Qureshi 2001).

3.30 In the second stage, a range of practice tools and guidance was developed in partnership with two local authorities. The aim was to introduce a greater focus on outcomes into care management practice (at both assessment and review stages), and to collect feedback from service users and carers. Three separate applications of the outcomes approach were developed and piloted, one of which was concerned with assessment of older people. Rather than produce yet another set of assessment procedures, the project’s intention was to insert a new stage between assessment and care planning which made intended outcomes explicit and therefore made the measurement of success possible. In practice, the research team identified how this stage would fit into existing procedures through discussion with managers and practitioners.

3.31 A two page summary sheet was designed for recording intended outcomes and how they should be achieved. The sheet was intended to be completed by the assessor and passed on to service providers. Service users and carers were not involved in the working groups at this stage as it was apparent from the first stage of the project that they were not greatly interested in details of procedures and case recording. However, as Qureshi reminds us (2001, p 27), literature written from the perspective of service users has argued for a greater focus in assessment on the aims of intervention rather than ‘needs’, impairments and deficits. This point is particularly pertinent when information is shared with service users and carers.

3.32 The pilot implementation involved 12 staff from both community and hospital settings, including 7 social worker/care managers, 2 senior practitioners and 3 home care organisers. A total of 30 assessment summaries and 17 staff diary sheets were completed by these staff and analysed by the SPRU team. The analysis showed that the ease with which staff adopted the outcomes concept was quite variable and that training resources were needed. Some staff clearly had benefited from being involved in the workshops while others were able to formulate outcomes appropriately without any training. For staff involved in the development process, discussion of the complexities of assessment helped to make explicit the underlying negotiation between users’ and carers’ needs on the one hand and agency resources on the other. Evaluation of the pilot was compromised, *albeit* for sound management reasons as the report explains, by the fact that the use of the outcomes summary was introduced at the same time as other changes to the assessment process (Qureshi 2001).
In her concluding comments, Qureshi (2001) argues that the assessment of outcomes through systematic recording and review is effectively the same as adopting standards for social care which in turn can be operationalised as eligibility criteria.

HOSPITAL DISCHARGE

Taraborrelli et al’s literature review (1998) commissioned by the Scottish Executive assesses the actual and potential contribution of current UK and European research to approaches to the discharge of frail older people (including those with dementia) from acute, geriatric and psycho-geriatric wards. The literature is discussed under four headings: pre-admission; following admission; preparing for the return home; and future research. While broad agreement was found within the literature on many aspects of discharge practice, weaknesses identified in methodology lead to suggestions for further research. Case studies of four Scottish NHS Trusts indicate diversity in discharge arrangements, reflecting both local variation in the needs of frail older users, and local differences in the pace of development of discharge policies. A number of innovative local discharge arrangements were in place in some Trusts with other agencies involved; but problems with funding, and lack of communication or involvement with other key personnel were also identified.

McGinley’s (2001) survey gathered views and experiences about hospital discharge from people contacted through carers’ organisations. This study was linked to a UK-wide study (Holzhausen 2001). It highlights problems which carers’ experience in relation to hospital discharge: having their caring contribution taken for granted; not being consulted about discharge arrangements; and patients being discharged before they are well enough. The findings are linked to policy recommendations which include taking account of the interests and needs of carers within the Delayed Discharge Learning Network.

Reed et al’s (2002) appreciative enquiry project referred to earlier aimed to address the multi-agency nature of successful hospital discharge. The researchers were successful in developing a collaborative approach to tackling complexities. The carrying out of the action plans was only limited by lack of engagement in the process of managers at a sufficiently high level within organisations involved. An example of practice-based research in Liverpool involved a ‘tracker nurse’ team formed in 2000. The team conducted a review to establish the factors which lead to emergency readmissions of patients aged 65+ and to try to prevent this (Rosbotham-Williams 2002).

3 A 2003 Scottish Executive Initiative
SUMMARY

3.37 Research on assessment practice is scarce. Analysis of how different professions approach assessment is potentially valuable in the development of multi-disciplinary assessment practice.

3.38 There is, equally, little published research on models of joint and integrated working in Scotland. Collaborative and multi-agency research has met with some success in England in actually promoting joint working. In one example, an action plan to improve hospital discharge was the outcome. In another, an integrated care system was developed employing a ‘whole systems’ approach with monitoring and evaluation playing an integral part.

3.39 Evidence of unmet need and of inadequate practice continues to emerge from research. Unmet needs for social support in older people with schizophrenia in one NHS Board area were found to be significant and attributable to a failure to provide multi-disciplinary assessment.

3.40 A Scotland-wide review of care management has revealed a high degree of variation in the way care management is organised and differing interpretations of what it is. Social Work Departments also appear to offer very different levels of service. 24-hour cover was available in almost all areas but only as an emergency or short term service. Managers from about half of the authorities did not think there was adequate choice for service users.

3.41 The policy agenda has focused attention on user satisfaction research. This has progressed in different directions depending on whether the aim is to measure or to improve performance. In English research, using global measures of satisfaction, assessment by a social worker, as opposed to a home care manager, was found to influence satisfaction in a positive way. However, such measures are of limited use for identifying what aspects of a service people find satisfactory or what needs to be changed.

3.42 An alternative approach focuses on outcomes of social care for individuals. Three different kinds of outcomes have been distinguished related to: maintenance of quality of life, change, and the process of service delivery. Researchers propose that agreeing outcomes with service users as a stage between assessment and care planning provides care managers with a tool to monitor standards of care.
4 SUPPORT AT HOME

4.1 This section brings together research on services delivered to people in their own homes. The studies of home care examine the range and quality of services and also the viability of intensive home care packages as an alternative to care home admission. Very few studies were identified which examined specialist services or innovative approaches to support at home. The exception was in the field of telecare – the application of smart technology in individual homes – where innovation in practice has attracted research interest.

HOME CARE

Quality of care – service user perspectives

4.2 Service user criteria for good quality home care have been well established by research. They include: reliability, continuity, care worker attitudes and competence, responsiveness of service, basing care around the needs of the service user. These qualities are confirmed both by Qureshi and Henwood (2000) from research on older people’s perspectives of outcomes, and by Raynes et al (2001) from a random sample survey of social services home care clients in Manchester. As Raynes observes in relation to recent debates about the definition of personal care: “The current emphasis on the provision of personal social care in home care services needs to be balanced by addressing the characteristics of quality home care services as defined by older people” (Raynes et al 2001).

4.3 Scottish research commissioned for the Scottish Executive Care Development Group in 2001 found that older people’s views about service provision were consistent with the model of quality identified in the English studies referred to above. This focus group study examined the attitudes of 49 older people to the issues surrounding free personal care. All of the participants used health and social care services and almost half were care home residents. The researchers found that on the whole participants were able to talk about their own experience of services and could identify their own unmet needs and gaps in services. Few were able to generalise about these matters or express opinions on issues such as ‘who should pay for care’ in the one hour allotted for the focus group discussion (Dewar et al 2001).

4.4 The researchers concluded that it made little sense to participants to prioritise services that they regarded as essential to their well being. The question as to which services should be provided free was therefore perceived to be irrelevant by participants. Categorising needs in terms of nursing care, personal care or living care, and defining needs in terms of specific tasks to be carried out by particular group of workers, the researchers argue, runs counter to the philosophy of care which places the user perspective at the heart of service delivery. The ability of individuals to articulate their own needs is the key to realising this philosophy and therefore the development of new methods to elicit users’ views should be a priority in the drive towards better quality services (Dewar et al 2001).

4.5 Current research at York University⁴, part of the Department of Health Outcomes Programme 2001-2005, is investigating what methods, management and resources make for flexible person-centred home care for older people. It aims to make practical recommendations about teamwork models, purchasing arrangements and resources which enable home care to respond flexibly, yet within realistic resources, to “heartfelt personal

⁴http://www.york.ac.uk/inst/spru/research/summs/homecare_oldpeop.htm
priorities” expressed by older people for whom they care. The literature review5 (Patmore 2002) provides a valuable source of UK and international material about models of home care provision.

Audit of home care

4.6 The Accounts Commission for Scotland study of home care (2001) is a rich source of information about the quality of home care from a range of perspectives. Services for older people in 6 local authorities were examined with respect to the range of services, costs, quality, and users’ and carers’ views. The study team worked with 6 volunteer councils who were conducting Best Value reviews of their home care services. Information was collected in a range of ways: postal surveys of service users, carers, staff and care managers; focus groups for users and carers; interviews with staff. Responses were received from 885 users (45 per cent) from an initial sample of 1950 users. From a potential 584 carers associated with those users in the sample who said they had a carer, 529 carers responded.

4.7 The lack of robust management information to support the delivery of home care in some of the local authorities participating hampered the development of performance indicators - one of the study objectives – and is presented as a key finding of the study.

4.8 The evidence collected in this study was examined in the context of five key areas of policy interest, the first three of which are of particular relevance to this review:

• achieving the right balance of care, examining whether there has been a shift towards the provision of care at home;

• whether a quality home care service is being delivered, including examples of quality measures;

• joint working;

• the management of home care service, and how information is used to support the delivery and development of the service;

• costs of providing home care and charging policies.

4.9 Analysis of Scottish Community Care Statistics by both the Accounts Commission (2001) and by Laing and Buisson (2002) concludes that the fall in numbers of home care clients since 1998 and the upward trend in the numbers receiving more than 10 hours of care per week is attributable to greater targeting and stricter eligibility criteria for home care services at the expense of less intensive practical help. However, the Accounts Commission detected a real reduction of 11 per cent in the number of home care hours employed by councils in the five years from 1996 to 2000. This suggests that overall, service reductions for less dependent people have not been matched by increases for more dependent people.

4.10 Home care was rated as good all of the time by 77 per cent of service users in the Accounts Commission survey - the remainder rated it as good some of the time - and by “almost two thirds” of the carers. Interestingly, home care workers surveyed were less likely than users and carers to rate the service highly - only 55 per cent on average did so. Between

5 posted at www.york.ac.uk/inst/spru
40 per cent and 70 per cent rated it as good or very good in meeting older people’s needs, showing considerable variation between councils (p13).

4.11 Involvement of service users in the assessment and review processes was found to need improvement. 40 per cent of service users had not discussed their needs with someone from the council for a year or more and only 15 per cent of carers had been asked if they needed support. Although it was apparent that formal reviews were not taking place as regularly as is desired, most home care workers (86 per cent) said they played a role in keeping managers informed about the changing needs of their clients. All the more surprising then that 69 per cent of home care workers said they were never involved in formal reviews (p 16).

4.12 A significant minority of service users said they did not have a choice in the day or the time when their home care service was provided. Choice in what home care tasks were carried out was more widespread though not universal (pp18-19).

4.13 In spite of the emphasis on personal care and accompanying changes in home care eligibility criteria introduced in recent years, the Accounts Commission survey found that 33 per cent of service users had help with housework. The importance of practical domestic help was reinforced by the kinds of tasks which service users would have liked more help with. The most commonly mentioned were cleaning windows, heavy housework and hanging curtains (p27).

4.14 Research has consistently shown a very high level of user satisfaction with the home care service in terms of how the worker treats them personally, and this survey was no exception. Dissatisfaction with home care can arise over arrangements for temporary cover. In this survey, 41 per cent of service users were always satisfied with the service they received when their usual care worker was not available and 46 per cent said they were usually satisfied (p22).

4.15 An important feature of the Accounts Commission results is the wide variation in levels of satisfaction with services between the respondents in different councils. This variation was also apparent in views about written information from Councils about the services and in knowledge about how to complain. It would be interesting to explore whether variations in supply factors such as staff training and turnover, and levels of sickness absence are associated with variations in satisfaction with different levels of service. This study did not attempt to account for these variations, and even if it had intended to it would have required more complete and consistent management information than appeared to have been available at the time.

4.16 The evidence on joint working presented in the Accounts Commission report is mainly in the form of examples of good practice. These include: shared electronic records; and specialist teams in which home care workers complement skilled nursing care to provide alternatives to hospital or residential care. The survey also reported a low incidence of sharing of care plan information: only 16 per cent of service users and around 50 per cent of home care workers had seen relevant care plans. Home care workers were even less likely to have seen a risk assessment for their clients.

4.17 The perspectives of home care workers (and of care home staff – see part 5) have tended to be neglected in research on quality of care. Recent research in Wales (awaiting publication by the Wales Office of Research and Development) has examined the factors
contributing to problems of recruiting and retaining home care workers. The research aims to support planning and policy making in dealing with the twin pressures of the anticipated increase in demand for home care and the need for home care services to meet national standards.

INTENSIVE DOMICILIARY CARE

4.18 The research literature on the development of intensive domiciliary care is reviewed in Curtice et al (2002, p 15-21). This review identifies ample evidence that flexibility in service delivery is a necessary condition for providing for people’s needs at home. Outside purpose-designed demonstration projects, this flexibility has been found to be difficult to achieve in the public sector because of the nature of existing employment contracts and the high costs of paying for care outside normal contract hours. The use of private agencies and the introduction of new job descriptions and designations for staff have played a part in increasing the capacity of councils to provide flexible care packages although in Scotland the process has been slower than in the rest of the UK (Curtice et al 1997).

4.19 Augmented Home Care schemes in Ayrshire and West Dunbartonshire were evaluated by Curtice (cited in Curtice et al 2002). Results highlighted the importance and the high cost of nursing input.

4.20 There is an extensive UK research literature, much of it associated with the Personal Social Services Research Unit (PSSRU) (reviewed in Curtice et al 2002), which analyses the costs, effectiveness and outcomes of home care packages. Research conducted by PSSRU in the mid 1990s (the ECCEP study – see part 3) involving 12 English local authorities, replicated earlier research (the Domiciliary Care Project) to allow comparison of findings and identification of progress. Amongst the conclusions, the ECCEP study found that one year after referral for a new or revised care package, the vast majority service users remained in the community. In addition there was evidence that the new community care arrangements had lead to greater emphasis on targeting, tasks, flexibility and indicators of quality (Bauld et al 2000, p368).

4.21 A study conducted by the Nuffield Centre for Community Care Studies (Glasgow University) explored the use of intensive domiciliary care across Scotland and its viability from the perspectives of service users, carers and staff (Curtice et al 2002). The study was conducted in Aberdeen, Edinburgh and South Lanarkshire in 1998–2000. Intensive support was defined as either 25 or more hours per week, 3 or more home care visits per day, or day care coupled with home care visits. The interview sample was made up of 150 older people who either had been assessed as being ‘at risk’ of care home admission or who were receiving intensive support. In 63 cases an informal carer was also interviewed. After nine months, 92 of the original sample of older people and 31 of their carers were interviewed again.

4.22 Qualitative analysis of interviews with service users and carers revealed that satisfaction of service users and carers with services was qualified - there was some dissatisfaction with the high number of care workers involved and with the reliability of staff cover arrangements. The most significant weakness in the service appeared to be the lack of proper care management and monitoring arrangements: respondents often felt that they were responsible for coordinating their own care packages. Inflexibility continues to present an obstacle in achieving satisfactory outcomes for people being supported at home. Factors
which limit the viability of intensive domiciliary care and ‘critical supports’ which can overcome them are summarised in the following four scenarios:

- the best outcomes for service users and informal carers are achieved when decisions are needs-led and systems are integrated with shared goals;

- when decisions are needs-led but systems are fragmented, users and carers find themselves having to take on more of the care management role than they would choose, the quality and reliability of services is not guaranteed;

- funding-led decisions within an integrated system of care management and service delivery provide reliable services but are more focused on risk and dependency than on needs and preferences - there is an assumption that informal carers will fill the gap if the person’s needs increase;

- the worst outcomes and least viable care packages are the result of funding-led decisions within a fragmented system - care managers have limited discretion and users and carers feel they are fighting for services - benefits of domiciliary over institutional care are reduced.

4.23 The Nuffield study included a comparison between the sample of people being supported at home with intensive care packages and a sample of 63 people who had recently been admitted to a care home. Only 12 of the 63 in the care home resident sample had received care packages prior to admission which met the study criteria for intensive support. 44 said they had not been offered additional help prior to admission. Only a minority (21 per cent) had made a positive choice to enter residential care. The majority appeared to have moved into care reluctantly and in the belief that there was no other option available. In contrast, 60 per cent of the community-based sample were still living at home nine months after first being interviewed - a somewhat lower proportion than was found in the comparable sample in the ECCEP study. The researchers conclude that intensive support is sustainable but that there is no evidence of a continuum of support whereby older people are offered appropriate choices as their support needs increase.

Palliative care

4.24 The role of community nursing in the provision of community care is touched on in a survey of palliative care provided in the primary and community care settings in Forth Valley. The survey found that in a 3 month period (1/1/1996 – 31/3/1996) district nurses were involved in the palliative care of 524 patients of which half were cancer cases. The majority of patients were aged over 65. A parallel survey of GPs indicated an annual total of around 600 receiving palliative care in the community. Nurses reported a higher proportion of non-malignant disease in their caseloads than did GPs. The report of the survey is not explicit about the content of the palliative care provided. However we can infer some of this from the perceived training needs indicated by nurses, including symptom control and development of counselling and bereavement skills (Hunter et al 1998; Dyer et al 1998).

EQUIPMENT AND ADAPTATIONS

4.25 A sample survey of waiting times for equipment and adaptations in 2000 collected detailed information from all 32 councils in Scotland (Hall 2001). The survey reported on the variability of waiting times both between and within local authorities and on the processes
employed in delivering the service. Good practice, particularly involving joint working, is highlighted in the report and linked to good outcomes in terms of waiting times. Service users and unpaid carers did not participate in the research and therefore ‘satisfaction’ is not measured directly in the study. Unfortunately it proved impossible to collect sufficient consistent data across all local authorities to provide a Scotland-wide analysis of waiting times - the difficulty of collecting data about service provision across local authorities is a recurring one. The analysis therefore relies on case studies to draw the conclusion that ‘sophisticated’ joint working arrangements, i.e. systems which go beyond simple joint equipment stores, are beneficial in reducing waiting times and waiting lists.

HOUSING AND SUPPORT

4.26 The Supporting People initiative to improve choice in housing and support had a long gestation period prior to its implementation in April 2003. Nevertheless there appears to be very little Scottish baseline research published to assist with assessing the impact of the initiative in the future. A study involving 11 cases drawn from 5 local authorities was published by Communities Scotland in 2003 (Craigforth 2003). This study was designed to provide a snapshot of housing and support options for people with particular needs before the measures of the Supporting People initiative had any impact. The report covers the relevant issues and proposes greater availability of specific practices to improve choice: independent advocacy, home ownership options, direct payments; early dialogue about housing and support preferences; and better information. However the study is too small to facilitate monitoring of the impact of Supporting People.

4.27 An evaluation of very sheltered housing in Tayside (Communities Scotland 2001) found that assessment of health and social care needs did not typically take full account of housing needs and that this could lead to existing provision being under used.

4.28 The development of new housing solutions for people who become dependent on support has been a neglected area in Scotland and the UK. In some countries, notably Denmark and the Netherlands, innovative small scale housing has been developed as alternatives to institutional forms of residential and nursing care. A new 2 year study of housing and care models commissioned by the Joseph Rowntree Foundation will compare and contrast a range of new housing models for later life. This study will cover the UK as a whole in mapping the range and number of innovative schemes. It will also review international literature relating to the strengths and weaknesses of different models of housing with care and support in a report due for completion in late 2004.

4.29 Exploring yet another aspect of dementia care (see part 7), research reviewed in Day et al (2000) has shown that the design of the physical environment can play a positive role in the care of people with dementia.

TELECARE

4.30 The use of smart technology to help maintain people in their own homes is currently being pioneered in a number of local authorities in Scotland. West Lothian’s project is on a large scale with the introduction of telecare timed to coincide with the closure of some residential homes for older people. South Ayrshire’s project highlights the benefits of

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6 Pleace N, Croucher K and Hicks L. A comparative study of housing and care models for later life. Funded by the Joseph Rowntree Foundation.
‘passive detectors’ for reducing risks for people with dementia who are living independently. Stirling University has been involved in evaluating projects in both local authorities and is currently conducting a longitudinal evaluation of the smart housing and telecare community care provision in West Lothian – to be completed in 2005.

4.31 The Stirling team have evaluated a pilot project (Home Comforts) which provided smart home technologies for 22 people in South Ayrshire (Bowes and McColgan 2003). Using qualitative research methods involving 8 service users, 6 carers and 12 staff, the researchers found that the use of smart technology had some positive effects. Comparison of care packages received over a 6 months period by ‘Home Comforts’ clients with those received by a comparator group showed that the hours of home care were more likely to have increased for the comparator group, that admissions to care homes and hospital were more likely and that GP visits were more frequent than for the group with the smart technology installed in their homes. These differences meant that the overall cost of care tended to be lower for the smart technology group.

4.32 The pilot phase of the West Lothian research (Bowes and McColgan 2002) follows on from earlier research conducted by Dundee University, which focused on users’ and carers’ perspectives (Gillies 2001). Gillies interviewed 21 of the first group of clients to receive smart technology installations at home in West Lothian, 5 home support staff and nine unpaid carers. Interviews with the clients covered the process of installation of the technology, people’s knowledge and understanding of it, and their future aspirations. Staff were interviewed about their work and their aspirations for themselves and for the smart technology project. Carers were asked about the effects of the technology on the clients and on their own care work, as well as being invited to comment more generally on the technology.

4.33 Key findings of Gillies’ work (2001) were that the project had achieved a range of successful outcomes. Many clients had continued to live in their own homes. They had generally become accustomed to the technology and appreciated its benefits. Difficulties with the technology were minor and generally practical. Carers were also satisfied with the technology, though it was not clear that their care work had reduced, or that they were necessarily willing to reduce it. The staff were proud of the achievements of the project, and appeared to be coping well with change and uncertainty at the time of interview.

4.34 Bowes and McColgan’s results from interviews with 14 staff, 12 clients and 3 carers in West Lothian were similar to Gillies’ (Bowes and McColgan 2002). They also found some evidence that the technology could be intrusive for clients and a cause of anxiety when things went wrong.

4.35 The full evaluation (see footnote 7) will explore the experiences and perceptions of the stakeholders in these programmes i.e. older people, unpaid carers and staff. Methods will include: case studies involving service users and informal carers; interviews with staff from a range of agencies; a value for money study; and comparison of the initiative with other models of care, using statistical measures and matched controls in another authority offering more traditional services.

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7 Bowes A and McColgan G Evaluation of ‘Opening Doors for Older People’ in ‘wired’ West Lothian. Funded by the PPP Foundation
4.36 Developing research methods for the full scale evaluation was a major aim of Bowes and McColgan’s pilot study and the instruments published with the report are a potential resource for evaluation of telecare in other local authorities.

SUMMARY

4.37 Research on community-based services demonstrates the centrality of users’ perspectives in achieving good quality services. As Dewar et al (2001) point out, people’s judgements about specific services are directly related to the effect of the service on the quality of their lives as a whole.

4.38 Evidence from research and audit indicates that overall in Scotland there has been a reduction in total home care provision at the expense of people with low level support needs.

4.39 Wide variation in satisfaction with services both from service users and home care workers is revealed (Accounts Commission 2001) but there is a lack of research on what contributes to this variation. The effect of factors such as management practices, service models, labour supply and training on quality as perceived by service users could usefully be explored.

4.40 One source of service user and carer dissatisfaction, noted in both the Accounts Commission and the Nuffield studies, is the limited use of care management to monitor and review needs once services have been allocated. In about half of cases surveyed by the Accounts Commission, home care workers were not involved in reviews.

4.41 The national survey of waiting times for adaptations and equipment identified an association between sophisticated joint arrangements and lower waiting times. However there is a lack of published research examining joint services and the lessons to be learned from different models of integration.

4.42 The studies of community-based palliative care focus on the input of nurses and medical staff and tell us that a high proportion of palliative patients in Forth Valley are older people with diagnoses other than cancer.

4.43 There is little research which examines the role of housing and support in community care networks. However, innovation in housing and support through the use of telecare has created a new area of interest for researchers. Ongoing evaluation of telecare projects is identifying a generally positive response for staff and service users. The Stirling University research is also focusing on developing evaluation tools which have potential for wider use beyond their own project.

4.44 A continuing theme is the problem of poor or inconsistent management information. This compounds the inevitable difficulties for researchers produced by local authorities employing different service configurations and different interpretations of national policy and guidance in their areas.
5 LONG-TERM CARE

5.1 We know from Census 2001 that 5 per cent of people in Scotland aged 65 and over live in ‘communal establishments’ – predominantly care homes – and that for the 85 and over age group the proportion is 22 percent. Slow progress in the development of viable housing and social care options, coupled with demographic trends, mean that communal living will be the experience of significant numbers of older people for the foreseeable future.

5.2 Quality of care, quality of life and the relationship between the two concepts is the subject of much of the research included in this section. Access to health care for residents is an aspect of quality of care which has received some attention: this review includes a study of physiotherapy and reference to ongoing palliative care research. The impact of staffing issues on quality of care is highlighted as a neglected topic. A UK wide survey of admissions to care homes is also included in this section.

QUALITY IN RESIDENTIAL AND NURSING HOMES

5.3 Research on quality of care and quality of life has contributed to the work of the National Care Standards Committee (NCSC) and continues to be of interest for the Care Commission. Research commissioned by the Executive in 1998 produced a literature review and developed a research based tool for use by inspection teams to monitor the part played by quality of care in contributing to residents’ quality of life. Although it was disseminated within the Executive, the various working groups of the NCSC and the Care Commission, the results of this project were never published.

5.4 The Accounts Commission (1999) evaluation of residential and nursing homes involved a self-selected sample of 39 homes. The survey undertaken included interviews with 318 residents and 47 relatives. The report concludes that quality could be improved in some homes without incurring extra cost by measures such as paying more attention to individual needs and requirements, developing better links with local communities, and integrated team working to give residents a smaller staff group to relate to. The report also includes many illustrations of good practice in involving residents and taking account of their individual needs.

5.5 Bland (1999) explores one of the main problems for older people facing admission to residential care – fear of losing their independence. Drawing on a wide range of literature relating to the development of institutional care, Bland compares two approaches to residential care provision. A case study of one private home illustrates the ‘service’ approach in which residents are treated as though they were hotel guests, their movements were not restricted and the normal conventions of privacy were observed by staff and residents alike. Staff treated residents, including those with dementia, as competent adults rather than as dependents in need of protection and residents needs and preferences were respected. Based on her own research and observation in care homes, Bland characterises the ‘social care’ approach as more akin to the hospital than the hotel. Overriding importance is attached in most care homes to minimising risk which leads to residents being kept under surveillance. Bland argues that the ideology of care implicit in this approach impedes the changes

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necessary to allow older people to retain their dignity and independence in a care home setting.

5.6 Quality of life in care homes from the point of view of residents is the subject of ongoing research by a team at Stirling University, part of the ESRC Growing Older programme\(^9\). The research explores perceptions of quality of life of frail older people during and after their transition to institutional care. A range of methods is used to seek the views of around 50 residents of care homes in central Scotland. The methods used include 24-hour observation of life in the home; interviews; and observation with individual residents and the use of Talking Mats\(^TM\) to support communication (Hubbard et al 2003; Murphy 1998). The final report of this research is expected in late 2003 and outputs include a video relating to sexual expression of older people in care homes.

**Staffing issues**

5.7 In their literature review on the role and world of the care assistant, Jacques and Innes (1998) highlight how little attention has been paid to this topic in spite of the increasing focus on person-centred care and the demands which this inevitably places on care staff. Jacques and Innes identify research which demonstrates the links between the experience of the care worker and quality of care. Jenkins and Allen (1998) for example, concluded in a study of stress and burnout in care staff that the degree of involvement which care staff felt they had in decision making was a “powerful predictor of resident-oriented care”. The nature of person-centred care has potential rewards for unqualified staff in terms of emotion and self-esteem. However, Jacques and Innes point out that the realisation of person-centred care is jeopardised in a system in which care staff lack qualifications and status and are rewarded with low pay for physically and emotionally demanding work.

5.8 Marshall has also drawn attention to this neglected issue in her discussion of food in care homes. She questions the quality of care achievable when care staff themselves may be inadequately fed as a result of poor wages and when rules forbid them from sharing meals with residents (Marshall 2001).

**Access to health care for care home residents**

5.9 The availability of health care to residents is an important component of quality of care in care homes and there is some evidence that increasing numbers of older people may become isolated from new developments in health care as they enter a care home. This issue is highlighted in a joint working party report of the Royal College of Physicians (2000) on health and care in care homes. They quote McCormack (1998): “shortening lengths of stay in hospital, and a decreasing commitment of the NHS to long-term care have exposed older people to real risks of missing rehabilitative opportunities”. The report goes on to detail the components of a desirable interdisciplinary approach to meeting the health and care needs of older people in care homes, and cites evidence of the positive impact on care outcomes achievable through the employment of specialist gerontological nurses (Ford et al 1998).

5.10 A study of staff attitudes to physiotherapy conducted in the mid 1990s throws more light on the accessibility of various forms of health care to residents in care homes (Chesson and Duthie 2000). The study, based on a sample of 20 private nursing homes in Grampian,

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\(^9\) Tester S and Downs M (grant holders) Exploring perceptions of quality of life of frail older people during and after their transition to institutional care. Funded by ESRC Growing Older Programme.
aimed to establish the likely need for and current extent of physiotherapy services in such settings. The analysis deals with (a) attitudes of staff to the appropriateness of physiotherapy services for older people and (b) care home policies regarding activities of daily living and availability of outdoor activities and exercise classes.

5.11 Sixteen out of the 20 matrons/officers-in-charge interviewed said they would suggest referral to physiotherapy for a 92 year old man who had had a stroke. In half of the homes residents did not take any part in activities such as keeping their rooms clean and in 5 homes there were no exercise classes at all. In other homes classes were of varying frequency and in only 5 homes was there any physiotherapy input into exercise classes. The researchers commented that “despite research evidence that exercise is beneficial in maintaining function in older people, it was not a common feature of everyday life in homes surveyed”. Some responses indicated low expectations of residents which the researchers felt might reflect ageism (Chesson and Duthie 2000).

5.12 Ageism is challenged by the relatively recent public recognition of palliative care as an appropriate ‘person-centred’ service for terminally ill and dying people in care homes, rather than exclusively for cancer patients. Palliative care explicitly recognises the spiritual, emotional, social and psychological needs of the patient as well as the physical and also depends explicitly on partnerships with relatives and other agencies (Hockley and Clark 2002).

5.13 The Bridges Initiative is a five year on-going palliative care project to develop knowledge of quality end-of-life care for the very old (to be completed in 2004). Findings from an initial survey of 73 independent nursing/dual registered homes in the Lothians are available from the project. The Lothians survey is concerned with the increasing number of people who end their lives in private care homes and the arrangements made for their care. Seventeen of the homes surveyed had over 40 per cent of residents dying during 1999 (the survey year), and over a third of all deaths had occurred within the first year following admission. More than half of the homes which responded said they ‘sometimes’ employed extra staff when a person was dying and 5 homes (out of 49) said that they ‘always’ did. Comments provided by respondents suggested that nursing homes are isolated from both palliative care education for staff and from much of the multi-disciplinary advice and equipment available to other NHS patients. Fewer than half of the homes responding had regular visits from a GP. Nursing home staff did not have access to medical records in the way that community-based nursing staff do. Where available, physiotherapy services were put to good use.

Quality of care in other European countries

5.14 Different approaches to long-term care provision are discussed in a transnational study by Tester (1999). In the Netherlands, evaluation of a national quality assurance system found that the crucial components were multi-disciplinary assessment and individualised care planning for multi-disciplinary care; protection and promotion of the rights of people with dementia; and the expertise of trained staff. Opportunities for involvement of family and community volunteers in the home and for residents to participate in the local community were also found to be effective. The report does not comment on methods of eliciting residents’ views. In both the Netherlands and Denmark the individual need for care or

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10 The contact for this ongoing research is Jo Hockley, Research Fellow/CNS(palliative care), St Columba’s Hospice, Challenger Lodge, Boswall Road, Edinburgh EH5 3RW
assistance is determined independently of the person’s residence – a care plan is a legal requirement. This is in line with current policy in Scotland towards providing support for younger people with support needs (although not currently embodied in law). However much less attention has been paid in Scotland to the need for genuinely person-centred care planning for older people when they move into residential care.

Advocacy for care home residents

5.15 Only one evaluation of an advocacy service for older people was identified for this review (CITS 2000). The service in question offered advocacy support to physically and mentally frail older people in long-term care settings in Edinburgh. Support was limited to short term or crisis interventions and the service was prioritised towards people with no-one else to turn to and to people moving out of hospital. Advocates would help their 'partners' to make informed decisions, have them implemented and have opportunities to access other services needed.

5.16 Findings confirm that advocacy is valued by partners and is effective in helping them defend their rights (p 20). The nature of advocacy work needed longer term involvement than that envisaged by the project. The project’s work was sometimes impeded by incomplete referral information and the partner's incomprehension of the advocate's role. The quality of relationship between advocate and agency was better when an understanding of the advocacy role had been established. In this project, individual advocates were responsible for assessing the need for advocacy of the partner to whom they were assigned. The evaluation notes that an alternative arrangement whereby the co-ordinator assessed the need and then matched advocates and partners accordingly would be worth considering.

5.17 Public promotion was seen as both complex and vital for the development of the advocacy service. The project planners had over estimated the initial response and a lack of appropriate referrals was soon evident. Personal visits to care homes, placements for trainee advocates and professionally designed posters were among the additional measures taken. The report concludes that these lessons might have been learnt from other advocacy projects since such experiences are not unusual (CITS 2000).

CARE HOME ADMISSIONS

5.18 The introduction of free personal and nursing care in Scotland will undoubtedly influence decisions about care but it is difficult to predict what the net effect on admissions will be. Of some interest therefore for this review is a large scale survey covering England, Scotland11 and Wales funded by the Department of Work and Pensions which aimed to identify the circumstances and probable outcomes of people aged 65+ being admitted to care homes as self funders. The survey was designed to allow comparison with an earlier survey of publicly funded admissions. The earlier survey did not include Scotland. Key questions asked in the report include: “Why do people go into a care home? Are people being admitted unnecessarily? To what extent are older people themselves involved in the decision? What affects their choice of home?” (Netten et al 2001).

5.19 Conducted in 1999, the survey achieved a sample of 921 new admissions to 292 homes, 65 per cent of which were residential homes. Information about the resident and their admission to care was in the main collected from managers and, where available, a person

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11 The sample excluded care homes to the north of the Caledonian Canal.
providing unpaid care prior to the admission. The perspective of the older person being admitted to the home was not therefore a focus of this study.

5.20 The study found lower levels of physical dependence in people who were self funders, but a higher incidence of disorders and diseases especially depression and malignancy, compared with those who were publicly funded. Cognitive impairment was less prevalent amongst self funders - 27 per cent had none compared with 20 per cent of publicly funded people and 16 per cent had severe impairment compared with 24 per cent (using Minimum Data Set Cognitive Performance scale (Morris et al 1994)). There was no statistical difference in behavioural problems between the two samples.

5.21 Prior to admission to the home: 21 per cent did not receive any services; 55 per cent were receiving some form of home care; 46 per cent received local authority organised home care on average 8 hours per week compared with 24-hours per week for users of privately organised home care. Comparison with the earlier survey found that publicly funded people admitted were more likely to have received home care (64 per cent) and received more hours on average.

5.22 The researchers suggest that admission of people with lower levels of dependency may reflect lack of access to adequate support at home – there was some evidence of frustration with level of service offered from comments added by relatives to the questionnaires. Not only were self funders receiving lower levels of care, the most able residents also exhibited a high level of unmet need for social participation and involvement prior to admission. It seemed likely that more self funders might have chosen to live in a care home because of their need for company.
SUMMARY

5.23 There has been a substantial amount of research on care homes focusing on quality of life for residents, research which has helped to formulate the principles and standards embodied in the National Care Standards. More detailed research on models of care would be useful in identifying how the principles and standards are realised in practice. The role of care staff and the relationship between job satisfaction and quality of care is a neglected area which has obvious relevance for management, training and quality assurance purposes.

5.24 More research is also needed to examine access to health care for care home residents as an issue of social justice. Studies of physiotherapy and palliative care address some important aspects of health care for frail older people. These studies draw attention to the risk of nursing staff in care homes being isolated from information and knowledge current in primary care teams and of ageist attitudes influencing access to specialist services for care home residents.

5.25 Experience in Denmark and the Netherlands suggests the possibility of moving towards a person-centred approach to residential care by distinguishing the care plan from the accommodation and challenging the rigidity of the care home service by offering more intensive support in a range of settings.

5.26 A study of one advocacy service for care home residents found that demand for and understanding of the service should not be taken for granted and that public promotion was essential to ensure take up (CITS 2000). The evaluation also found that longer term involvement by advocates with their partners was needed than had originally been envisaged by the project.

5.27 UK wide research on people admitted to care homes on a self-funding basis revealed that they had received relatively less in the way of support services prior to admission than publicly funded people (in and earlier survey) (Netten et al 2001). Self funding people were less likely than publicly funded ones to be physically dependent, but more likely to suffer from diseases or depression and to have experienced social isolation in their own homes. These findings suggest that there is unmet need for community-based services offering social contact and interest as opposed to intensive personal care.
DEMENTIA CARE

6.1 Dementia care is assigned its own section in this review because of the high level of recent research activity in this area compared with others. New approaches to dementia care are reflected in the way much of the research has been conducted. The research reviewed includes issues for people from minority ethnic groups and people living in remote and rural areas. The potential for not only self expression but also choice and control are the subject of research on people with learning disabilities and dementia.

6.2 In a review of dementia research published in 1998, Moriarty produced a set of key findings from research which remain relevant today.

The prevalence of dementia is difficult to determine because identification of people with dementia in primary care is variable and little is known about how social services identify dementia in non medical referrals.

There is increased public awareness of dementia as well as new drug therapies and this has affected the stage at which people are informed of their or their relative’s diagnosis. The need for access to counselling and support has been more clearly articulated as a result.

People from minority ethnic groups are becoming a growing proportion of people with dementia. Accessible and culturally sensitive services are needed to meet their needs.

Intensive domiciliary care if reinforced by intensive carer training and specialist care management may enable people with dementia to remain in the community for longer.

Our knowledge of the potential for community services is hampered by evidence of variations in provision.

People with dementia living in the community are especially likely to be reliant on the support of a single person, usually their spouse or adult daughter.

Carers’ psychological health is likely to be poorer if they are caring for a person with dementia and providing substantial amounts of care. Lower levels of depression have been found in carers who were more knowledgeable about dementia.

NEW APPROACHES TO DEMENTIA RESEARCH

6.3 Until the last 15 years or so the prevailing view of dementia amongst concerned professionals was that of a condition of inevitable and unpleasant deterioration in physical and mental functioning (Walker et al 2001). From that perspective, care is seen in terms of keeping the individual safe from physical harm, of meeting physical care needs and of using medication to temper ‘difficult’ behaviour. Whilst this view still has its adherents, an influential psychosocial approach to care of people with dementia originated with Tom Kitwood and the Bradford Dementia Group has been developed in the UK and internationally, and notably at the Dementia Services Development Centre at Stirling. It is based on the perception that “at least some of the symptoms that are commonly found might
be due more to a failure of understanding and care than to a structural failure of the brain” (Kitwood 1997). One explanation given for this new focus is the influence of the new emphasis in the NHS on the autonomy and human rights of patients coupled with developments in nursing theory away from a purely medical model towards holistic care (Walker et al 2001).

6.4 Dementia care mapping (DCM) developed at Bradford as a practice tool has been widely used in research as a means of measuring the quality of care received in formal settings from the standpoint of the person with dementia (Walker et al 2001; Barnett 2000; Brooker 2002). The technique involves systematic observation of people with dementia over a number of hours. Well-being or ill-being is rated for activity observed in 5 minute segments. Activity is identified from a list of 24 behaviour categories e.g. eating or drinking, participating in exercise. Well or ill being is also recorded in relation to non interactive behaviours e.g. unattended distress, being withdrawn.

COMMUNICATION: HEARING THE VOICE OF THE PERSON WITH DEMENTIA

6.5 Building on earlier research (Goldsmith 1996), researchers at Stirling explored different approaches to communication with people with dementia. This produced evidence that many people with dementia, including those with significant communication difficulties, can, with the right kind of support, take an active role in communicating their thoughts and feelings about services (Allan 2001). The main outcome of the project has been a set of training materials to support staff and managers in exploring the area of service user consultation.

6.6 An important feature of this project was that care staff themselves rather than researchers undertook the direct work on communication with service users. Given the starting point of the study – that people with dementia can communicate - the staff, their attitudes and motivation are a central focus of the project. These staff were working in a variety of settings including day centre, care homes, a hospital ward and a counselling service (the project’s resources were insufficient to include either domiciliary services or services for minority ethnic groups).

6.7 In her report’s conclusions Allan draws attention to some of the obstacles encountered, for example, resistance to the idea that communication with service users could be ‘work’; and lack of confidence initially in both service users and staff in their ability to communicate. The ‘techniques’ used to assist the communication process were essentially aids rather than formulae to be applied in any situation. Allan discusses factors which were found to promote communication such as attention to pacing and timing, confirming Goldsmith’s earlier conclusions. Her final point relates to “…the need for staff to develop and maintain a strong sense of meaning in their work with people with dementia. It is this which will enable them to operate in the most sensitive, creative and personally rewarding way.” (Allan 2001, p114).

6.8 An analysis of non-verbal behaviour in people with dementia based on ethnographic, participant observation - a method explicitly based on the observer’s interpretations of behaviour - adds further to our understanding of the capacity of people with dementia to communicate (Hubbard et al 2002). Findings from this study, which was carried out in a day centre in Scotland, suggest that encouraging non-verbal forms of interaction between carers and people with dementia, and between each other, can mean that more people with dementia are included socially in the group.
Advances in communication methods through development and research mean that researchers now have reliable techniques available for both observation and interviewing with people with dementia. The day care evaluation discussed below (Walker et al 2001) exemplifies the application of these complementary approaches.

Different cultural perceptions of dementia

The confusion and anxiety of dementia sufferers from minority ethnic groups has been found to be exacerbated by the lack of culturally aware services (Anderson and Brownlie 1997; Scott 1998; Patel et al 1998 cited in Netto 2001). A recent exploratory study of living with dementia as experienced by South Asian people (Bowes and Wilkinson 2003) draws attention to cultural differences in the way people perceive dementia and the influence this has on what kinds of support they need. The authors argue that cultural variation is such that the only meaningful approach to meeting needs is to offer person-centred mainstream services to all on an equal basis. This approach would avoid stereotyping minority ethnic groups and avoid excluding groups such as gypsy travellers or religious communities who also have distinctive cultures.

Evaluation of day care services

An evaluation by Queen Margaret University College is a good example of the new approach to dementia research because of the fullness and quality of the published report. The approach to and methods used for data collection and analysis are clearly explained in the report, covering issues of ethics, quality assurance and participation. In this study a combination of methods was used to evaluate two different day care settings: a day hospital and a day centre. The study involved: a structured questionnaire for staff on organisation and culture; focus groups and interviews with 21 staff; interviews and DCM with 10 service users with dementia; and interviews with 14 informal carers. The research team attended the settings weekly over a 2.5 month period. DCM and interviews with people with dementia was carried out by experts in dementia care from the Royal College of Nursing and the RCN consent process for promotion of well-being in people with dementia was used.

The evaluation focused on the extent to which the stated philosophy of the services is translated into practice and the therapeutic aims of dementia care are pursued. In one of the settings there was a lack of fit found between what staff perceived to be the well being of their clients and what was revealed about the quality of care by the DCM analysis. Detailed evidence from DCM is presented to show how left unattended sociable individuals fared well in the day care setting whereas less sociable people were withdrawn and disengaged. A high level of group activity stimulated by staff produced higher levels of enjoyment and well being amongst day care attendees but at some cost in terms of one to one contact.

The main benefit of the day care service identified by informal carers was respite. Although they identified the company, stimulation and affection as valuable benefits for their relative, they were not aware of the potential for therapeutic benefits and therefore had no expectations in this regard. The report’s authors conclude that respite for carers is not a sufficient justification for long-term funding of day care. National standards and professional education are needed to support high quality day care which both enables the carer to feel supported and provides therapeutic experiences enhancing the well-being of the person with dementia, and indirectly the carer.
6.14 The researchers observe in their recommendations that while improvements in dementia care practice are needed there are “possible sources of resistance” to change. These include: the low status of care work with people with dementia, the power and prestige of the medical profession; the “dead weight of tradition”; and the influence of the medical model on doctors, other staff and family carers (Walker et al 2001).

CHOICE FOR PEOPLE WITH DUAL IMPAIRMENTS

6.15 Increased longevity of people with learning disabilities and concern about how their needs can be met prompted a Joseph Rowntree Foundation funded study to examine how far people with dementia and learning disabilities are involved in making choices and decisions about their own lives. The 20 participants lived in Scotland in a variety of settings and care arrangements. They were all diagnosed as having dementia or were awaiting assessment. Their ages ranged from late-30s to mid-70s and most were around 50 years old (Stalker et al 1999b).

6.16 The researchers point to previous research which has shown that opportunities for older people with learning difficulties to make choices are not determined solely by their abilities but also, and more importantly, by the attitudes of staff. This point is well illustrated in the Rowntree study. The research participants often had clear preferences about what they wanted their lives to be like but most were prevented from making decisions and choices, in part because of the attitudes of those around them. A number of practical pointers are put forward to remedy this: paying attention to how people communicate; being willing to tolerate risk; allowing enough time for people to take in information; allowing staff time to grow familiar with the people they are supporting; and offering people practical tasters of services to help them choose (Stalker et al 1999b).

6.17 The degree of control which people with a learning disability and dementia have over their lives is the subject of ongoing research at Edinburgh University. This study stems from observations that people with learning disabilities who develop dementia are usually moved out of their homes and into nursing home care. The study aims to develop best practice guidelines for supporting such people to stay in their own homes and communities by analysing what community, inter-organisational and service responses are most effective12.

DEMENTIA CARE IN REMOTE AND RURAL AREAS

6.18 Small scale qualitative research sponsored by the Carnegie Trust presents views of people with dementia and their carers about their support and their experience of living in rural areas of Scotland (Innes et al 2003). The study aimed to redress the finding of an earlier study of service providers in rural Scotland which highlighted the exclusion of people with dementia in service provider consultation processes. In this follow-up study the researchers aimed to demonstrate the value of seeking the views of this particular group of service users.

6.19 Seventeen people with dementia (4 of whom were Gaelic speaking) participated in face to face semi-structured interviews. All lived in remote and rural areas and there was no...

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attempt to compare their responses with the responses of people in more urban areas. Participants praised services which:

- encouraged a social life (11 responses)
- provided stimulation (9)
- were appropriate for their needs (9)
- provided care that was “loving” and more than just “going through the motions” (8)

Staff putting in additional effort, be it in time or duties carried out (6 responses) and the feeling of having “connected” with the service provider (5) were also among the positive comments.

6.20 Participants criticised services when they found the care on offer disorientating (5 responses) or distressing (1), inappropriate for their needs (5) and when they disliked the service provider (5) or other service users (3).

**SUMMARY**

6.21 There now exists in Scotland an active and productive network of researchers applying and extending new research methods which focus on ‘hearing the voice’ of the person with dementia. This network is part of a wider international network of researchers whose work is closely linked to innovation in practice. The enthusiasm and commitment of research in this field is distinctive and has generated methods and approaches applicable beyond the field of dementia care.

6.22 Dementia research has established that, given the motivation and appropriate training, researchers and others can communicate meaningfully with people and include them in research. Collaboration between researchers, practitioners, carers and people with dementia has lead to the development of methods for observation and interviewing which can contribute to better care. One study found that by encouraging non-verbal interaction between carers and people with dementia, more people with dementia were included socially in a group.

6.23 There are cultural differences in how dementia is perceived and therefore person-centred approaches and services are the key to understanding and meeting the needs of people with dementia from different ethnic groups.

6.24 The main benefit of day care as perceived by unpaid carers is respite for themselves. However Walker et al’s (2001) day care evaluation, using interviewing and Dementia Care Mapping to include the perspective of the service users themselves, reveals the therapeutic value of the service.

6.25 Research on the potential for people with learning disabilities and dementia to exercise choice and control emphasises staff attitudes and the need to allow time and space for people to make their choices.

6.26 The study of people in remote and rural areas provides an illustration of the potential for people with dementia to express their views.
7 DISCUSSION AND CONCLUSIONS

7.1 What does the research covered in this review contribute to promoting effective community care for older people and what more could be done? The purpose of this final section is to draw conclusions about what topics are adequately covered by research and what areas need attention.

7.2 One of the difficulties inherent in a review of this type is that however the material is sub-divided there is a risk of running counter to a basic principle of community care: person-centred approaches and integrated systems are not promoted by discussing services separately. For this reason, this final section is structured around a set of themes prompted by the review and by current policy concerns and relevant for community care research in general. The themes are:

- gaining a Scotland-wide view;
- promoting collaboration and new models of joint working;
- hearing the voice of service users and carers;
- taking account of minority ethnic groups;
- exploring issues of equity and ageism;
- analysing the effect of workforce issues on quality of care.

Gaining a Scotland-wide view

Key point 1  Research could contribute more to a Scotland-wide view of provision for older people if better use were made of existing data sources, including national surveys and information collected by the Scottish Executive for monitoring purposes.

7.3 This review identified very little research which can properly claim to give a Scotland-wide view of community care. Two obvious reasons for this are highlighted: one related to resources and the other to the different interpretations made of community care policy and guidance by different stakeholders.

7.4 Limited resources in terms of timescales and budgets mean that studies which achieve Scottish coverage are limited in the depth of information they are able to collect (Stalker and Campbell 2002). More in-depth studies (Accounts Commission 2001; Curtice et al 2002) limited to small samples of local authorities can claim to be representative only to the extent of including urban and rural areas and contrasting models of service delivery.

7.5 Marked variation in how local authorities implement policy causes problems for research which aims to produce a national picture or to compare one local authority with another (Hall 2001; Stalker and Campbell 2002). The problem for researchers arises from the lack of a common language shared not only between the Scottish Executive and local authorities but also between local authorities. Consultation with local authorities is the standard way for common understanding of data collection requirements to be achieved and this is the practice used in the development of annual statistical return systems. For one-off
research exercises consultation of this kind is more limited by time and other resources. This raises the question of whether reviews/snapshots should be conducted in ways which are replicable so that better use is made of investment in research and change can be tracked over time.

7.6 The same argument could be applied to data collected by the Executive for administrative purposes. Monitoring the implementation of policy is a key function of the Scottish Executive which collects large quantities of data in the form of, for example, responses to letters, consultations and community care plans. Some of these data may be of value for research, providing a basis for more in-depth or longitudinal investigation than is called for by the immediate needs of administration. The collecting and processing of the data could be made more efficient by using simple database techniques for storage and retrieval. This would mean that data were stored and instruments retained for use in repeat exercises when required as well as being available for research purposes. This has two obvious advantages: firstly saving on time and effort in developing new instruments; and secondly the possibility of observing change by comparing two or more time periods.

7.7 Hinds et al (2001) in their review of data sources for social research identify strategic issues of relevance for this review. They emphasise the cost of collecting good quality data and the need to exploit existing data whether collected for statistical, research or administrative purposes. This requires increased awareness of existing data sources and readiness to share information paying proper attention to ethical and data protection guidelines.

7.8 Longitudinal datasets maintained for health service research in Scotland include 1921 and 1936 Scottish Birth Cohorts and the MIDSPAN Studies in Renfrew/Paisley (Hinds et al 2001). Since 1999 the Scottish Household Survey (SHS) has provided a rich source of information about older people living in households. The value of SHS data will increase over time.

7.9 Very limited use has been made to date of the SHS as a source of information about need for support and use of services. For the first detailed analysis of 1999 SHS data relating to older people (MacDonald et al 2001) complete data on care given and received were not available. A second, ongoing analysis of data collected in the first 4 years of the survey will present results on older people’s self-perceived need for and use of formal and informal care services. This analysis will present Scotland-wide results but there is also scope for using the SHS for comparison between local authorities.

Promoting collaboration and new models of joint working

| Key point 2 | Action research and other participatory approaches bring service users’ perspectives to the heart of the service development process. There is scope for more collaborative research and development work in Scotland and better dissemination about successful projects. |

7.10 During the 1990s a body of evaluation literature grew up around new kinds of projects providing integrated nursing and personal care for very dependent people in their own homes. This review uncovered remarkably little more recent research evaluating new models of joint working. We have plenty of evidence from research of the shortcomings of
community care delivery and its failure to provide what older people want, but relatively little from which we can learn about successful ways of working.

7.11 In part 2 of the review, older people’s priorities for improving and maintaining their quality of life are presented in research by MacDonald (1999), Bowes and Dar (2000) and by Nuffield (1998). Findings from these studies clearly show the issues which have to be tackled by agencies providing social care, health care, transport and housing, and the need for collaboration between agencies if community care is to be more responsive to older people’s needs and aspirations. However research of this kind is of limited value unless it feeds into planning and development.

7.12 Milligan’s (2001) and MacDonald’s (1999) research draw attention to the importance of consistent funding for community-based groups and services. Milligan also highlights differences in the extent of community care networks in urban compared with rural areas directly attributable to demographic factors.

7.13 Evaluations commissioned by health and social care agencies and available only as ‘grey’ literature were outwith the scope of this review. An ongoing review of joint practice is needed based on such literature and using information submitted to the Joint Future Unit by NHS boards and local authorities in the form of plans. It would be helpful for findings from such a review to be published at regular intervals on the internet.

7.14 The experience of collaborative research and development appears to make a positive contribution to the aims of improving practice, breaking down professional barriers and involving service users and carers. The review identified innovation in England in the form of research and development exercises such as the hospital discharge study described by Reed et al (2002) and the EPICS project of Foote and Stanners (2002). These projects use research as a stepping stone towards achieving more person-centred practice and tackling problems in a holistic way. Scottish work of this nature, if it is taking place, is not represented in the published literature.

7.15 The review uncovered surprisingly little evidence about health and social care agencies working jointly and the effect this has on outcomes for service users and carers. There is a need for more published material in the form of independent evaluation of innovative practice to inform us about what whether and how such practice works effectively. There is also a need for published evidence of the effectiveness of community development and action research methods in bringing about effective joint working.

Hearing the voice of service users and carers

| Key point 3 | Active collaboration between researchers and practitioners has produced a wealth of new methods and insights which allow people with dementia to be included in discussions about their care, something which was unheard of ten years ago. Health and social service research has a great deal to learn from dementia research about how to ‘hear the voice’ of service users and carers. |

7.16 The phrase ‘hearing the voice’ is associated with research and development in the field of dementia care which aims to overcome communication barriers between people with dementia and others. Work in this field has shared common interests and techniques with work involving people with learning disability. There has been considerable progress in dementia research since Moriarty’s 1998 review when she commented that research effort to
find ways of evaluating services from the perspective of people with dementia was at an early stage. Researchers and practitioners now have available an impressive body of literature to guide them in communicating with and consulting people with dementia about the services they use.

7.17 Research on the views and experiences of people with dementia discussed in this review provides abundant evidence that communication and consultation is possible provided appropriate methods are used, and enough time taken. This research has implications for practice in terms of how individual carers and professionals relate to people with dementia. It also has implications for service providers and planners who in the past have looked to third parties to speak on behalf of people with dementia.

7.18 The techniques of observation described and methods of support for communication developed by researchers in the fields of dementia and learning disability also have wider application. Research with frail older people, people with sensory impairments, and people with distinct ethnic and cultural backgrounds may all benefit from the inclusive and sensitive approaches discussed in this review.

7.19 Use of such approaches are fundamental to what Harper refers to “restoring the individual to the centre of the research question” (see Introduction). They are also relevant in participatory and collaborative research in which service users and carers are playing a part. The ‘active involvement of service users and carers in research’ required by the Research Governance Framework is meaningful insofar as the mechanisms for involvement allow people’s voices to be heard.

Taking account of minority ethnic groups

| Key point 4 | We know more now than five years ago about the experience which older people from minority ethnic groups have of community care. More research is needed involving people from a wide range of ethnic groups and parts of Scotland to help to overcome ignorance and prejudice which stand in the way of more equitable service provision. |

7.20 Some progress has been made since Harper’s conclusion, that little was known about older people from minority ethnic groups, their use of services or their requirements (see Introduction). We now have a body of research literature providing insight into the nature and causes of inequalities experienced by such groups. Most of the studies referred to are small-scale, based on Glasgow or Edinburgh and concerned with the Pakistani and Indian communities.

7.21 For professional practice, the research referred to in the review can be helpful in promoting a more person-centred approach generally. It is not necessary to commission research on the specific needs of every ethnic and national group resident in Scotland to find out that people with distinct languages and cultures require sensitive treatment involving people with knowledge and understanding of the language and culture. Nevertheless case studies of particular groups, if disseminated appropriately, can play a part in tackling ignorance and prejudice.

7.22 The scale of inequality is indicated by one comparative study (Bowes and MacDonald 2000) highlighting the low uptake of home care and aids and equipment amongst older South Asian people. Comparative research based on larger geographic areas including
small towns and rural areas is needed so that progress in addressing inequalities can be tracked.

**Exploring issues of equity and ageism**

| Key point 5 | Social justice requires all older people to have similar access to basic health and social care whether they live at home or in a care home. There is some evidence that care home residents may be isolated from particular health and other services. More research is needed, based on large representative samples, to establish the extent of such inequity and to inform solutions. |

7.23 Given the priority afforded to social justice issues in Scotland, gathering evidence of inequality in access to services is an important function of research not wholly confined to research on cultural and ethnic groups. There is very little firm evidence but a widespread perception that older people in general are victims of ageism in the way services are organised and allocated.

7.24 Residents of care homes may be at risk of being cut off from access to community-based health care services such as chiropody, occupational and speech therapy, physiotherapy and dentistry. Research based on large, well-constructed and representative samples is needed to explore these issues thoroughly.

**Analysing the effect of workforce issues on quality of care**

| Key point 6 | The characteristics of the workforce who provide basic care is a neglected area in community care research. Improving quality depends on the recruitment and retention of staff who can be trained and motivated to provide person-centred care. There is currently very little evidence as to whether this can be achieved. |

7.25 The availability of trained and well-motivated carers to staff statutory and voluntary services and to act as volunteers is crucial for community care. The review by Jacques and Innes (1998) establishes the link between aspects of job satisfaction for care staff and quality of care for residents. However the current review identified virtually no published research since that review was completed which examines the impact of recruitment and retention of staff, characteristics of care staff, casual and short term employment on reliability and quality of care. Anecdotal evidence gathered by the author in the course of her own research suggests that the recruitment and management of casual staff in the voluntary sector absorbs disproportionate amounts of manager’s time at the expense of time spent meeting with and reviewing the needs of clients.

7.26 High turnover of care staff in the statutory services and reliance on agency staff in care homes are also factors which might be expected to impact directly and indirectly on the quality of care. Issues of recruitment and retention of home care staff are the subject of a research report about to be published by the Welsh Office of Research and Development. This will be of interest in Scotland where such issues have yet to receive proper attention in the context of community care. An examination of recruitment and retention of professional social work and community nursing staff is also needed.
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ANNEX  RESOURCES USED

Libraries and Library catalogues

Age Concern Scotland
Dementia Services Development Centre, Stirling
National Library of Scotland
NHS Health Scotland Library
Stirling University Library

Databases

Ageinfo
BIDS
British Nursing Index
Caredata

Websites

Centre for Social Policy Research and Development, University of Wales at Bangor
Chief Scientist Office and related research unit sites
Communities Scotland
ESRC
Joseph Rowntree Foundation
Journal of Dementia Care
INVOLVE (Consumers in NHS Research)
Nuffield Centre for Community Care Studies, Glasgow
Personal Social Services Research Unit, Universities of Kent, Manchester and LSE
Scottish Centre for the Promotion of the Older Person’s Agenda (Queen Margaret University College)
Scottish Dementia Network
Scottish Executive publications
Scottish Executive Social Research
Scottish Hub for Access to Research and Evidence (SHARE)
Scottish Partnership for Palliative Care
Scottish School of Primary Care
Social Policy Research Unit, University of York
UK National Collaboration on Ageing Research (new in September 2003)