SPRU
SOCIAL POLICY RESEARCH UNIT

TOWARDS FLEXIBLE, PERSON-CENTRED HOME CARE SERVICES

A guide to some useful literature for planning, managing or evaluating services for older people

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FOREWORD

SPRU initially conducted this literature review in order to provide guidance to a new research project. This report now aims to share the fruits of the literature review with a wider audience of people who are managing, developing or inspecting services for older people. The literature review was designed to gather information about: (a) different ways in which older people's home care services can be organised (b) how older people's services can be customised to reflect the values and choices of each individual service user. Information on both topics is quite rare and the following summary of literature can benefit a much wider audience than the SPRU research project which inspired the enquiry.

In particular it can benefit:

- anyone who is designing, developing, managing, evaluating or inspecting home care services for older people, whether from a purchaser or a provider perspective

- anyone who is working to promote older people's own influence on the services they receive or to promote respect for the values and choices of older people.

This report covers many studies from a variety of countries. But perhaps particularly useful are its substantial summaries of the following, which represent important knowledge for anyone managing or developing home care for older people.

- A major recent British research study into management factors affecting quality and effectiveness of home care services

- Little known in the UK, a body of pioneering research by an American research team into adjusting an older person's services to their values as an individual.

- Two pioneering experiments by UK Social Services Departments in increasing choice and influence by older people as individuals over the services they receive.

For some readers' purposes it may suffice to read this report selectively, picking relevant passages. However there is a strong case for reading the Introduction in full, which explains the purpose of the literature search, in order to understand what follows.

For those interested, information on future parts of this SPRU research project which prompted this literature search is given as an Appendix.

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SPRU's research project on flexible, person-centred home care for older people

Box 1: Differing individual priorities among older customers of a home care service.
(*Source: Patmore 2001a*)

Mr A was 70 years old and suffered severe mobility difficulties which entailed 18 hours Home Care per week. But he had engagements outside his home seven days a week - largely connected with his substantial church and voluntary sector roles. He named only one priority concerning Home Care, which was help to get up at 8.00 am punctually every day to be ready to be collected for his various meetings. Nothing else was important. He was content with service from 10 different Home Care Assistants. He had no interest in staff flexibility concerning small extra tasks - thanks to the large social network which his community work sustained, he said he could phone people who would give him such help whenever necessary. Likewise, although he lived alone, his active lifestyle meant he did not need Home Care for company. He was extremely satisfied with Home Care because the service already went out of its way to supply him with the early first visit on which his lifestyle depended.

Mr B was 83 years old, lived alone and his health problems meant that he rarely went out. He greatly valued conversation with certain Home Care staff. His top preference was that he should be always served through three particular Home Care Assistants, rather than the six who currently visited. He did not wish to receive all service from a single Home Care Assistant because he had previously found this made staff changes too painful. He strongly wished to know in advance who would give him his next visit. Also, if he did not feel like lunch, he wished Home Care Assistants to be allowed to spend their allotted time talking with him instead of cooking. But staff punctuality was not greatly important to him, as long as staff would eventually turn up.

Mrs C also would have wished service from fewer staff and felt weary about instructing new people. But her chief desire was that Home Care staff should always sit down and briefly chat with her at the end of every visit. If there was anything worrying her that day, she would only be able to raise it during such a conversation. Otherwise she could not articulate it.

Mr D actually liked service from many different staff because of the refreshing variety of people he met this way - he lived alone and otherwise saw few people. He felt his Home Care workers gave him as good a service as they were allowed to give. His priority was help with two problems with which Home Care were not allowed to help - cleaning upper inside windows and hedge-trimming. He feared that his cloudy windows and overgrown hedge gave neighbours a false message that he had “gone to pot”.

TOWARDS FLEXIBLE, PERSON-CENTRED HOME CARE SERVICES

A guide to some useful literature for planning, managing or evaluating services for older people

1. INTRODUCTION: REASONS FOR THIS LITERATURE SEARCH AND THE RESEARCH PROJECT OF WHICH IT IS PART

This literature search was undertaken during the first phase of a research project which began as follows. During SPRU's research interviews with older users of home care services in an earlier project, it was noticed that some individuals would name particular things which they sought from their home care service, which could have a major impact on that individual's satisfaction and quality of life. Examples are given in Box 1. It was reasoned that a direct route to increasing benefits from home care and to improving service quality might be for staff to invest efforts in fulfilling, where possible, each individual's top priority requests.

But many Social Services Departments have been investing their efforts to promote home care quality in a somewhat different direction. They have developed sets of standards concerning the most common issues of importance to users of home care – like staff punctuality or service from a few familiar workers - which are then applied to *all* home care customers. These standards are often inspired by the pioneering research of Henwood *et al.* (1998) into the views of home care customers. Henwood and colleagues conducted focus groups and individual interviews with users of home care and, by aggregating the information from these, identified some aspects of quality commonly mentioned by service users - like staff reliability, desire to be served by staff whom users knew well, and for staff to be willing to help with a broad range of household problems. From this they developed a home care quality assurance framework for Social Services Departments. Some Departments now promote uniform quality standards for home care which emphasise for all customers punctual visiting, providing service from only a few different staff, and consistent completion of tasks on a list available to the customer (for example West Berkshire Social Services 2000). Such approaches concentrate on developing a single set of responses, which will suit the greatest number, rather than explore how the service can respond differently to different individuals.

SPRU's observations however suggested a case for investing effort in whatever areas matter most to each individual, rather than in achieving for everyone some common standards which for some people may have little importance. For instance, in Box 1, while Mr B and Mrs C show older people's frequent preference for a few familiar workers, this does not apply to Mr A and Mr D. Also, Mrs C and Mr D express priorities which are so individual that they would never feature on a list of standards derived from pooling service users' comments and selecting the most common. There would seem a case for seeking to respond to each person in whichever way would matter most to them.

The key difference between the individual-centred approach now being examined by SPRU and the quality assurance approach of Henwood *et al.* (1998) is *how* service users' views are applied – whether they are treated on an individual basis or applied collectively. The actual service user concerns noted by SPRU (e.g. Qureshi *et al* 1998, Patmore 2001a*)* and by Henwood *et al.* (1998) seem generally very similar. The latter clearly encountered requests for help with cleaning windows or small household repairs or to be taken on outings (Henwood *et al.* 1998) – the sort of requests which feature prominently in SPRU's project. Recently another study of older people's values concerning home care has been undertaken by Raynes *et al.* (2001), using an approach similar to Henwood and colleagues. Its examples of service users' concerns are plainly similar to those in Henwood *et al.* (1998) and Patmore (2001a). All these studies are hearing older people expressing a similar range of views; but they are marshalling this information in different ways and proposing different ways for Social Services to use this information.

SPRU explored the idea of an individual-centred approach to quality in home care during two research studies, as described in detail in Patmore (2001a). In one of these studies, in-depth interviews were conducted with random samples of older users of community care in two localities by one Social Services Department. These included questions about any preferences or requests concerning interviewees' home care. They also sought interviewees' views on the times at which they received their visits and the number of different staff who provided these, since these topics are now common subjects for Social Services quality standards. In a second exercise, questions about customers' preferences were included in the test of a new staff briefing document which gave important facts about each customer. Here an intention was to find whether listing such questions led staff to discover customer preferences which they did not know already and whether they would then be able to meet them. This briefing document was tested within a third locality covered by the same Social Services Department.

The following picture emerged from these two exercises.

- Around half or two-thirds of older users of home care would name a request or preference of some sort. A few people named two or three.

- Requests / preferences differed widely among individuals.

- Some requests or preferences were already known to home care staff; others were not.

- Some of these requests or preferences were already being met; others were not.

- Some requests or preferences became known and actually followed by home care staff as a result of the experiment with the briefing document.

- Some requests or preferences had evident major importance for the person concerned; others seemed less evidently important. A question seemed evident whether the requests of certain individuals should receive priority in view of potential benefits, all aspects of people's circumstances considered.

- Localities differed in what were the most common requests. One reason seems to be the character of local service. Common requests may reflect its particular limitations and hence differ from service to service. Differences in population many be another reason.

- Some requests touched the boundary of what home care staff were allowed to provide. There seemed a case for placing these on the agenda for possible service development.

- While many older people did name as important that their visits came at particular times or from a small number of staff, there were also many others for whom these issues were not important. There were several people who actually enjoyed meeting a variety of service-givers.

- Face-to-face discussion with customers, like a review, seemed important for eliciting preferences or requests.

- Older people can say much more about their preferences or requests concerning home care once they have received service for a few weeks, than they can before they have tasted the service. Preferences or requests may easily change over time, as an older person's circumstances change, so the subject could usefully be revisited at every review.

- There were signs that the fulfilment of some categories of individual customer requests can be tracked through ordinary service records. So there might be opportunity to include these in audit or formal monitoring of quality.

- Some major family carers, who in Patmore (2001a) were all the wives or husbands of home care customers, also nominated specific types of help from home care which would make their own lives easier. It seemed that an individual-centred service could helpfully seek requests separately both from the actual customer and from any major family carer.

Thus an individual-centred approach to service quality seemed a practical possibility. But its value would depend on how well staff were able to respond to requests thus elicited.

A major question raised by SPRU's various observations of individual requests and preferences is why some home care teams can meet types of request which other teams say they cannot. For instance some home care services find private cleaners, plumbers or repair workers as a matter of course if their customers request this, whereas there are others which say this is impossible. Some services routinely limit the number of different workers per customer, whereas other services say it is pointless to discover customer requests on this subject since they cannot fulfil these. Some services seem to have little trouble with providing visits at fixed times, whereas others seem unable to do this. SPRU has found some services where management names the changing of light-bulbs as a standard part of home care – but many more services where managers prohibit this completely. Are there ways of running a home care service which give it greater flexibility for fulfilling a good range of the more important

customer requests? How services organise staff rotas and cover for staff absences affects their ability to meet certain requests, like service from staff members whom a customer knows well or to guarantee service at particular times. Are there some systems which provide greater flexibility than others? Some service user requests are not met because of some services' sweeping rules against things like taking customers outside their homes, changing light-bulbs or finding private cleaning or repair services. Certainly there are some genuine problems which such rules are intended to prevent. But are there not successful examples of more flexible policies which sometimes fulfil such requests while still avoiding problems?

If meeting older service users' requests, like those in Box 1, is important, a step forward would be to seek systems for providing home care which are flexible enough to meet such requests. SPRU seeks practical models for organising a local service whereby, for instance, each of the individuals in Box 1 could have their requests met. The centrepiece of SPRU's new research project on flexible, individual-centred home care is an examination of how well a small set of home care services, deliberately chosen for their variety, can respond to requests which are important to service users. We wish to discover what teamwork models, policies and resources make it feasible to respond to different types of older people's requests.

This research's goal is practical recommendations to services nationally about teamwork models, procedures, policies and resources which enable Home Care to respond flexibly, yet within affordable resources, to heartfelt personal priorities expressed by older service users. Details of the full research project are included as an Appendix.

The first stage of this research project - before the study of the small set of home care services - was to seek whatever knowledge from other sources might assist the project. Hence a literature search was undertaken with a dual focus:

- Any research on different practical models for organising or managing home care services, since the project was going to examine the influence of service organisation and management on responsiveness to user preferences and requests.

- Any research on responding to values, preferences and requests among older people on an individual level. SPRU's project had already been much encouraged by the work of Colhoun (1998) with Kensington and Chelsea Social Services' home care provision. It was possible that other such sources of inspiration or guidance might exist.

Following a description of how the literature searches were conducted, the results for each of these points of focus will be described in turn.

2. METHODS OF LITERATURE SEARCH

1) Information on how home care services are organised

One set of searches was directed towards literature which reviewed or evaluated different models for delivering home care and, more broadly, any which simply described practical arrangements whereby home care services were staffed and managed. While the project's remit concerns older people, the searches addressed home care in general since many home care services for older people also serve other client groups. (In the event, despite these broader parameters, very little relevant literature was discovered.)

2) Information on eliciting and acting on differences between individual older people in their values, priorities or expressed preferences concerning support for everyday living

Since this is a relatively new topic, it seemed likely that literature might be relatively scarce. Accordingly, this second set of literature searches extended beyond home care to any sort of supported living situation, whether in one's own home or in residential care, and embraced the work of care managers as well as home care services.

Search strategies

Searches conducted:

The NISW Caredata database was searched, using the following keywords, which were system-based where possible (that is using the keywording conventions of the database).

Teamwork + home care
Teamwork
Home care + organisational structure
Home care + care management
Home care + case management
Supported living + teamwork
Home care + models
Home care + management
Home care + older people
Home and community-based services
Preferences
Values

Four hundred and twenty eight references were generated.

(Caredata contains over 50,000 abstracts of books, reports and articles from a wide range of journals in the social care field - UK, North American and other English-language sources. Most of its information is post 1985.)

Next, the ASSIA database was searched for all references under:

Homecare
Domiciliary care

This generated 102 references.

Abstracts or database summaries of these references were read to identify any which might be relevant to either of the aims listed above. Wherever this seemed likely, the document was obtained and its relevance determined. Twelve of the documents obtained were discarded at this stage on the grounds that they were less relevant than anticipated from abstracts.

Additionally, twelve documents already known from other sources were included. Also the literature review by Boaz *et al.* (1999) was studied for references relating to service users' preferences.

Concerning Aim 1, only two studies were identified which had substantial relevance. Some others were identified which supplied information of peripheral relevance.

Concerning Aim 2, contrary to expectations considerably more papers and articles were found. However, the most informative material came from a single team of researchers, while there was only one other substantial source of information. While other sources contributed helpful information, this was on a much lesser scale.

3. FINDINGS FROM THE LITERATURE: MODELS FOR HOW HOME CARE SERVICES ARE ORGANISED

No research was identified which actually listed a variety of models for how home care services can be organised. Much of the literature on home care describes the needs of service users or discusses issues or problems in serving them. Even when a literature review, like the review of outcomes by Godfrey *et al.* (2000), explicitly identifies and compares different models of home service, this is done in terms of the differing aims of programmes and differences between their clienteles, rather than examining differences in *how* they organised their services.

Two research studies stand out as considering aspects of how home care is organised (Schmid and Nirel 1995, Sinclair *et al.* 2000). While neither itemises models for service organisation, both identify management issues which are important considerations in any model for managing or organising home care. In addition, Sinclair *et al.* (2000) draw attention to factors which require attention in any description of models of home care service. Two recent surveys of the home care workforce likewise highlight factors which merit attention (Mathew 2000, Taylor 2001). A study by Olsson and Ingvad (2001) on staff-client and staff-staff relationships in home care services has some important implications for this project. It is Sinclair *et al.* (2000) which on all fronts is the most useful resource. Relevant aspects of Schmid and Nirel (1995) and Sinclair *et al.* (2000) will now be described, followed by Olsson and Ingvad (2001).

Schmid and Nirel's study of how management policies affected satisfaction among clients and staff in Israeli home care services

Schmid and Nirel (1995) examined the balance between managers empowering staff to act autonomously and managers controlling and regulating how staff served clients. Considering the varied and changing nature of older people's needs and the delays involved if staff must keep consulting supervisors, clients are likely to have their needs better met the more staff are empowered to respond autonomously to whatever needs their clients present. However autonomy and empowerment of staff can also present problems for clients if it means staff follow their own wishes, not requests from clients. Favouritism may govern how staff allocate their time. Staff may simply abuse autonomy to do less work than they are supposed to. Thus there are also ways in which systems for managers to control staff can also benefit home care clients.

Schmid and Nirel surveyed 41 Israeli home care organisations, mostly independent sector agencies of varying sizes - roughly 80% of their work paid from public funds. Interviews were held with service users, with management representatives, and with home care staff. For around a third of the 317 clients interviewed, efforts were made to interview the staff who actually served them. Questions covered management control and supervision of staff, adaptation of services to individual clients' needs, the equity and fairness of management policies from the viewpoint of both staff and clients, and client satisfaction. Working conditions and training for staff were also investigated.

Results included the following. Clients were more likely to be satisfied the more they felt an agency gave them a say in their services and the more they felt it treated them fairly. The more that staff felt they were treated fairly, the more they were satisfied with their jobs. Staff generally gave more positive ratings the more they were empowered by managers to make decisions. Staff training seemed to have large positive effects on the

satisfaction of both staff and their clients. Better working conditions for staff seemed on balance linked to better performance. But there was no evidence of any effect on service quality from the amount of control exercised by management over staff. On balance there seemed a case that services benefit from clients and staff being given greater leeway to decide themselves how services should be provided. Another finding was that clients had clear, strong perceptions concerning the actual staff who served them but only a hazy image of the organisation which employed these staff. Staff members may strongly colour clients' experience of the service. The authors comment: "the elderly person has direct contact with the home care worker, who is responsible for delivering the services and providing support. The relationship is based on mutual respect, empathy and love which contributes to the quality of the services."

From Schmid and Nirel's study it can be helpful to bear the following in mind during any examination of models for home care service:

- How much a service gives staff autonomy in deciding on day-by-day service giving.
- How much a service gives clients autonomy in determining day-by-day service giving.
- Staff training.
- Staff working conditions.
- The importance of relationships with individual home care workers in shaping an older person's experience of a home care service.

'Management and effectiveness of the home care service': the study by Sinclair et al. (2000)

Sinclair *et al.* (2000) studied a sample of home care services within four English local authorities. This sample included both services managed by social services and independent sector agencies working on contract to social services. A key aim was to identify differences between services' performance, as judged by clients and staff, and to then find explanations for these differences. A combination of postal surveys and interviews with clients and staff was used. As in Schmid and Nirel's study, efforts were made to interview some staff whose clients could also be interviewed about their performance. In this case, as well as clients passing comment on these staff, the same staff had also been rated in interviews with these staff members' managers. One hundred and three different home care organisers, 1,389 other staff and some 750 service users participated in the study at some level.

One central conclusion parallels Schmid and Nirel's observations. Sinclair *et al.* distinguish on the one hand 'service performance', which embraces things like the suitability of the amount of home care time supplied, of the timing of service delivery, or of the number of different staff who serve an individual. 'Service performance' was appreciably higher in some service units than in others and this seemed to reflect management practices. On the other hand they identify 'staff performance' as a separate element - and this involves the personal qualities which staff show to clients, the skill with which they perform caring tasks, and their sensitivity to clients' needs. This

aspect of home care service was generally independent of organisational style and managers' practices; it seemed to have much to do with the personal qualities of certain staff, rather than being something which managers develop. However it did require some conditions which reflect a service's organisation - adequate time spent with clients, good communication and teamwork among staff, and systems which allowed staff enough repeated contact with the same clients to get to know them.

For any study which examines organisational aspects of home care this is an important message - that the strong personal qualities of certain basic grade home care staff are a major influence on clients' evaluations of their services and that this may sometimes outweigh benefits from well-crafted management systems. Very notably, Sinclair *et al.* (2000) point out that sometimes such staff took action in their own, unpaid time to counter what they saw as shortcomings of their service's official limits to provision - for instance doing clients' laundry in staff members' home washing machines, contrary to a common rule. The authors comment: "The more the staff perceived the organisation as not working in the interests of clients, the more they were prepared to work for them in their own time". Thus any study which seeks to examine the influence of particular management approaches to home care perhaps needs to try to separate the effects of the personal qualities of front-line home care staff. It also needs to recognise that to some extent its assessments of service quality may be confounded if, in a sort of difference levelling effect, altruistic staff members in 'badly managed' teams are reducing their services' shortcomings through extra work on their own initiative.

Another key issue raised by Sinclair and colleagues is whether home care staff should be used for more complex and ambitious purposes than common at present and their work somewhat modified to fit this. At present, home care services are commonly used in what Sinclair calls a "practical/bureaucratic model" which focuses on the delivery of practical services like meals and personal care. However Sinclair *et al.* see evidence that some home care staff are well-equipped to play a more complex role as keyworkers for older people, who monitor all aspects of a client's well-being, liaise and co-work with health and social services staff when necessary, and provide emotional support. This reflects their vantage point of frequent, intimate contacts with older people and their capacity for forging good relationships with them. Sinclair names such aims for the service a "professional/integrated model". He sees it as entailing a generally more professional role for some home care staff, involving more training, more autonomy of action, and closer links with occupational therapists, social workers, nurses and doctors - and more supervision in view of the greater demands of this expanded role.

In studying how home care teams are organised it is useful to bear in mind that there are these contrasting standpoints about the purpose of home care. While Sinclair's "professional/integrated model" may not be commonplace, it may soon gain greater prominence as health and social service managements combine, since more call is likely to be made on home care staff to contribute to the work of health professionals.

Alongside such conclusions, the study by Sinclair *et al.* (2000) provides much descriptive information about variations among the 103 home care teams which were managed by the home care organisers who participated in the study. The study does not categorise these into models. However useful information is supplied concerning topics which deserve attention in any study of home care services. For instance:

- How easily can home care for an individual client be changed by providers without permission from social services care managers. At some services, provider managers can themselves authorise changes in type of help given, in the timing of service, even in the amount of time provided. At others, all of these things require permission from care managers. A key variable for any home care service is the respective balance of power between care manager and provider manager to modify services.

- What type of supervision is given to staff and how often. This varies widely between services.

- Are the managerial functions for a team supplied by a single manager? Or are they spread among a set of managers of different seniority?

- Large variations exist in the size of teams and in the number of hours worked by staff members. Some teams, for instance, comprise many workers, each working only few hours per week.

- It is always vital to examine how a service addresses provision at weekends and during public holidays. This is often a source of problems for older people whose services may be good during weekdays. Some local authority home care providers rely on independent sector agencies serving their clients during weekends and public holidays. A service's approach to evening, weekend and public holiday provision must be deemed part of its model for service even if the service avoids covering these times itself.

- Always examine how a service provides cover for staff who are unavailable through illness, holidays or job changes and how it manages sudden needs for extra help which are frequent among older people. Sinclair *et al.* anticipate that the services with systems which coped with this best tended would probably cost more.

- Also important is how a service manages the times of peak demand - around getting clients up in the morning, meal times and bed times. These peak periods dominate many home care services. Does a service address them through employing many part-timers only at these hours? Or does it use fewer staff, each working longer hours, and stagger the times at which clients receive services?

- Another key issue is whether staff members have guaranteed hours of work each week. Some services, typically local authority, may employ staff, full-time or part-time, during set hours each week. Other services may still guarantee part-time staff a set number of hours but wish each week to choose when these hours are worked so as to suit the service's current needs. However some services, typically independent sector, pay staff only when there is work for that staff member to do, so that if a client dies that source of the worker's income ceases immediately unless the agency has a new client needing service at that moment. Whether or not a

service guarantees staff hours has enormous ramifications for how it can function. The effects are complex. Each arrangement brings its own strengths and problems.

Sinclair *et al.* also direct attention to the very different experiences - for both staff and clients - which can arise from common differences between the work arrangements at independent sector and local authority services. They noted that often at independent sector services staff members worked fairly few hours and these were spent with a small number of clients whom they got to know well as a result. Rarely were they in a rush with their work because they did not have other work to rush on to and, since they had fewer clients each, there was less chance of emergencies which could make them late for subsequent clients. In contrast staff at some local authority services visited twice as many clients, knew them much less well and faced an obviously larger number of situations which could cause them to arrive late or in a rush on subsequent visits. Their clients might have a very different experience of care.

Lewis and Sawyer's critique of care management

Arguments for "professional/integrated" home care in Sinclair *et al.* (2000) are amplified in *Rediscovering the community care approach* (Lewis and Sawyer 2000), a discussion paper concerning some problems in current home care. In brief, it describes a particular model for organising home care services which was demonstrated to work well and points out that conventional care management arrangements can act as a barrier to the provision of user-centred home care. It calls for the development of alternative means for commissioning services.

The model described by Lewis and Sawyer includes the following features. A manager has responsibility (and appropriate devolved budgets) for meeting a complete range of needs for a small (15 - 30 clients) caselist - either through interventions by themselves, by a small home care team which they directly manage, or by other agencies which they purchase or broker, short-term or long-term, as client need indicates. A complete range of needs includes, in one of Lewis and Sawyer's examples: "... personal care; mobility and transfers; meals including special diets; laundry; banking and bill paying; shopping; transports to appointments and for social activities; helping to fit hearing aids and other means to communication; organising the gardening; monitoring medications; rehabilitation support; treatments such as eye drops; providing respite care at home; home maintenance; advocacy; emotional support and pet care. But the support is not limited to a specific list of activities or tasks." (Lewis and Sawyer 2000). Such a service must respond swiftly and flexibly to whatever new needs emerge among its clients and the team's combined skills, versatility, knowledge of clients and staff freedom of action must match this challenge. The service must be able to respond at all times necessary - including evenings, weekends and public holidays. Another feature of the model is the use of small numbers of familiar staff to provide each client's services. For instance each client may have a keyworker, who is both their routine home care worker and a person who communicates any emerging needs back to the team, backed by some other familiar staff who can give service when the keyworker is not available. Importance is placed on adapting service to each client's preferred lifestyle and habits. Clearly it is a model which is well placed for responding to individuals' values and preferences.

Lewis and Sawyer cite two practical demonstrations of this model - both developed

outside the current British service commissioning arrangements for home care. One is a current Australian home care system (Mathur *et al.* 1997). The other is British but precedes today's system - it is the Darlington project from the 1985-88 Care in the Community initiative (Challis 1995). Lewis and Sawyer point out that this successful project was gradually dismantled when transferred to mainstream services where, in the early 1990s, the distinction between health care and social care was becoming accentuated and the present divide between purchaser and provider was being introduced.

Reasons for conflict between this service model and current practices in commissioning of services include the following. In the view of these authors, the care manager/provider relationship introduces scrutiny, control, even mistrust of the provider by the purchaser. Such control by purchasers involves specifying services in precise detail and requiring providers to make contact whenever they see a case for changes. This inhibits providers from responding swiftly to changes in older people's needs and disregards their on-the-spot knowledge of their clients. Service users themselves may not be able to effect even small changes in their own services without permission from care managers. For instance, SPRU's 2002 telephone interview survey found that quite commonly the timing of home care visits is initially contracted by care managers according to the client's preference at the time. But, months or years on, the client may not be able to subsequently revise their own preference without their provider seeking permission from care management - sometimes involving a lengthy re-referral procedure in the case of long-established clients. Another disadvantage, Lewis and Sawyer point out, is that purchasers' concern to specify all permitted tasks in advance leads to a overly narrow, stereotyped range of permitted tasks, since it is impossible to predict the diversity of necessary forms of help which periodically arise. There are large time costs from purchaser/provider negotiations and from duplication of assessments and reviews. Lewis and Sawyer argue that alternative approaches to commissioning and purchasing home care must be developed and that some autonomy for providers is essential if service users are to be the focus of services.

One crucial message from Lewis and Sawyer's paper for SPRU's project is to examine the contribution of purchasing/care management arrangements to the performance of any home care service. It is a message which, as mentioned earlier, also emerges from Sinclair *et al.* (2000).

Another message is to keep in mind aspects of the home care service model for which Lewis and Sawyer argue and which also fits the prescriptions of Sinclair *et al.* (2000). It clearly is well suited to respond to service users values and preferences.

Patmore's study of team organisation in two intensive comprehensive support teams for mental health service users

An interesting addendum on the subject of models for comprehensive service is a very detailed description of two small experimental social services teams in a late 1980's set of mental health demonstration projects, funded by the Department of Health (Patmore 1991). These two teams served a small number of especially challenging long-term users of mental health services. Most of their clients were aged under 65 and services ranged from conventional home care roles in the case of some clients to a focus on companionship and social enablement for others. These teams delivered a very great

variety of help, as and when needed, ranging from shopping and cleaning to leisure outings, household repairs, welfare benefits advocacy and even, on occasion, court injunctions to protect a client from harassment. Notable features of organisation and management in these social services teams were:

- A three-tier hierarchy whereby a qualified manager and deputy managers supervised unqualified staff and directly co-worked with them, as required. Between them, managers and deputies undertook a significant amount of service-giving.

- A calculated variety of expertise was introduced by the appointment of staff with nursing, social work and welfare benefit expertise to the manager and deputy manager posts. One team included a part-time handyman.

- Teams developed systems whereby contacts with each client were provided by a small number of staff who got to know that client well. Each client had a keyworker who co-ordinated their services. But this keyworker was backed by one to three co-workers, depending on the client's needs, so that someone whom the client knew should always be available in their keyworker's absence. One team experimented with using some staff wholly for the co-worker role.

- Long weekly team meetings were used to discuss new needs and any problems among clients, to plan responses, and to modify staff rotas for the next week as required.

- While keyworkers played an important and responsible role in respect of their clients, all clients were unquestionably clients of the whole team. Major issues in an individual's care were decided by discussion at team meetings and with team managers, not by keyworkers alone.

- In addition to one-to-one work, these teams developed some resources which could be shared by several team clients, like regular leisure outings by mini-bus or a social drop-in.

Some obvious barriers would confront this team model today. They were very well resourced - though arguably the model could be adapted to somewhat straitened circumstances. Some current versions of care management would stymie their swift and flexible response to new issues among clients, as Lewis and Sawyer (2000) have contended. Also, considering that the independent sector is becoming the major supplier of home care, it is worth noting the problems for staff meetings and development work under independent sector auspices, since conventional service purchasing often does not directly fund such activities. Understandably, independent sector managers need very good reasons before authorising any activities which do not deliver financial returns.

Olsson and Ingvad's study of staff-client and staff-staff relationships in Swedish home care

Olsson and Ingvad (2001) conducted a study of perceived emotional atmospheres in staff-client and staff-staff relationships in home care. This supplies some noteworthy messages for how services are organised and managed.

Olsson and Ingvad interviewed clients and staff from home care teams which served people aged over 65 in seven varied home care units in Sweden. Clients and the staff who served them were separately asked to choose adjectives to describe their relationship, drawing from a list of supplied adjectives. Staff were also asked to comment in the same way on the atmosphere within the team where they worked. Information was also collected about factors like the number of different workers serving each client, each team's history of organisational changes, and the amount of collective staff influence on team decisions noted via observation of team meetings. Some conclusions relevant to the management of home care services are as follows.

- The more that they were served by many different staff, clients were more likely to use a cluster of negative adjectives to describe their experience - like 'uncertain', 'irritated', 'confused', 'impersonal'. They were also less likely to use adjectives which reflected good relationships than if they were served by the same few workers all the time.

- When a client was receiving their care from only same few workers, their staff were more likely to use positive adjectives to describe the staff-client relationship and less likely to be concerned with the burden of the work or to describe their work in negative terms.

- Clients were more likely to use negative adjectives (like 'uncertain', 'irritated', etc) about their home care, if they were served by teams where there were conflicts among staff. To some degree, too, adjectives which reflected good relationships were more likely to be used by clients served by teams where staff shared decision-making.

- Perhaps surprisingly, if a home care team had an atmosphere of conflict, its staff were *more likely* to use positive adjectives associated with closeness of relationship to describe their relationships with clients. But, as just mentioned, clients of such teams tended to view negatively the service they received. Thus staff in these teams seem prone not to notice the negative feelings quite common among their clients. Olsson and Ingvad comment that this type of team may worsen the deterioration of a staff-client relationship, vicious circle fashion, once this has begun. Its clients are more likely to feel unhappy about service, but staff may be less likely to recognise signs of clients' discomfort and hence not respond constructively. Clients' misgivings about the service may deepen in consequence.

Team conflicts might affect clients through clients observing staff mood, the authors comment, or through direct staff comments to clients or through the inconsistencies in service delivery and failures of staff-staff communication which are likely when a team is not functioning well.

The authors draw the following conclusions for practical management of home care service:

> "It is important to establish a high personal continuity of the worker delivering the care and to build stable work teams with open communication and high cohesion. The worker must be able to create and maintain a constructive emotional climate with the recipient in her/his home. Therefore it is important to train the teams to create an adequate group climate. The leader must be close to the team and be aware of the perspective of emotional climate in the care work. The leader must also be prepared to give support to home care workers in critical situations."

Olsson and Ingvad suggest that staff from teams with conflicts were more likely to fail to perceive clients' dissatisfaction, than were staff from cohesive, supportive teams. But what happens if staff belong to no team at all? SPRU's 2002 telephone survey found that in some home care services staff meet each other frequently, both formally and informally, whereas in others the staff rarely meet other staff apart from their managers. In many UK independent sector agencies, for instance, staff do not really belong to teams. But even where staff do not belong to a team there can still be an emotional atmosphere surrounding a worker's relationship with managers and the agency which employs them. This may have its effects on the care they give.

Useful messages for research on home care include the importance of team atmosphere, where staff belong to a team, and attention to management activities intended to create a good relationship between employer, managers and home care staff.

But a particular message from this Swedish study is to examine what organisational conditions make it easy to supply a client with service from a small number of consistent, familiar workers since this appears such an important positive factor in shaping both parties' experience of care. This study adds to the case for respecting the widespread preference among service users for such an arrangement.

4. FINDINGS FROM THE LITERATURE: INDIVIDUAL PREFERENCES AMONG OLDER PEOPLE CONCERNING THE TYPES OF HELP THEY WISH AND THE LIFESTYLES THEY DESIRE

The most helpful literature found comes from research at the University of Minnesota. Two key figures are Rosalie Kane and Howard Degenholz, who have investigated and promoted an approach whose aims are close to that of the new SPRU project. The first work summarised will be a general review of approaches to the values and preferences of older service users as individuals (Kane 2000). A summary will then be given of some important experimental testing of this approach (Degenholz *et al.* 1997, Kane *et al.* 1999). Relevant messages for the SPRU project from the work of Kane and Degenholz will then be discussed. Finally, mention will be made of some additional messages from other authors on the same general subject. Two of these, Colhoun (1998) in Kensington and Chelsea Social Services and Clark and Spafford (2001) with Portsmouth Social Services, will be discussed at some length. Others are then summarised more briefly.

Kane's review of approaches for including values and preferences in the assessment of older people

Kane (2000) provides an important overview of issues and practical approaches in this area. Key points include the following.

- Currently recognition is given to the importance of adjusting services to individuals' preferences only in situations where an older person is no longer able to communicate their preferences. For instance, a reasonable degree of attention is now paid to ascertaining in advance people's wishes for how their care would be managed close to death. Likewise there is attention to strategies for identifying preferences of people with dementia who may become unable to communicate these themselves. But what is conspicuously lacking, in Kane's view, is comparable respect for older people's preferences and values when they *are* able to communicate them.

- There is mixed evidence concerning how far information gained about a person's values and preferences should be used later on, when a person cannot voice their wishes owing to dementia or other disorders. There is some uncertainty whether values and preferences remain constant in dementia. However this information can always be applied prior to dementia and, as just mentioned, Kane regards services as commonly displaying a blind spot as to such opportunities.

- Kane views values and preferences as conspicuously under-represented in assessment procedures - considering quite how many other topics that professionals do include in assessments.

- Assessing values and preferences requires investment of time in discussion with an older person.

- It is desirable that values and preferences are assessed in a face-to-face conversational exchange whenever possible. However well documents can be

designed to record preferences, on their own they are no substitute for such exchanges.

- Discussion of values and preferences, for instance during an assessment, will increase an older person's awareness of their own preferences. It may also stimulate family members to think constructively on the subject.

- Care is needed if applying aggregated information about individual preferences to service planning. Certainly some occasions arise when this is useful. However caution is necessary lest the meaning of individualised preferences is lost. "'Average preferences' for a group may be statistical artefacts that end up reflecting no person's views." (Kane 2000)

- It is unproductive to spend much time debating how terms should be defined. Certainly there are conceptual difficulties in assessing 'values and preferences' (Kane's own preferred terms), even in defining what these mean. For instance, people revise their preferences according to their perceptions of how likely they are to be fulfilled. They may voice more preferences the more they discuss the subject. Plainly there are some preferences which are important, whereas others seem trivial. Much opportunity exists for enlarging on semantic uncertainties. Nevertheless it is possible to conduct clear practical demonstrations that there is opportunity for improving older people's care through investigating individuals' values and preferences. It is important to bear such practical demonstrations in mind (cf. the empirical studies by Kane and Degenholz) and not to exaggerate the importance of conceptual problems.

Kane identifies a set of topics which are frequently important to include in assessments of an older person's values and preferences.

- Preferences concerning how the basic routines of everyday home life are conducted.
- Preferences related to religious practices.
- Preferences related to privacy - including in which domains privacy most matters to each individual.
- An older person's stance concerning how far they are ready to take risks with their own safety in order to live in a way which they value.
- An older person's stance concerning what sort of control and choice they wish to exercise over the services they receive.
- Preferences relevant to choosing appropriate care and accommodation after a person leaves hospital.
- Preferences concerning various types of housing in old age - feelings concerning different aspects of ordinary housing, sheltered housing and residential care and how these compare in desirability.
- How a person would like to be treated when they are close to death. For example, the sort of policies on health care and resuscitation which they wish to be followed. For example, any people whom they wish to take decisions on their behalf, if they can no longer communicate.

Kane presents some examples of instruments for assessing older people's values and preferences, though commenting how generally rudimentary is the development of this

area. She points out some general issues concerning instruments for this purpose. According to Kane, instruments for investigating this subject need the following characteristics.

- They need to be able to elicit and record wholly idiosyncratic individual views. Yet they benefit if they also have some structure which will enable comparisons.

- On the one hand they need to investigate preferences in terms which are sufficiently specific to be informative and distinguish between individuals. On the other hand, too great a degree of specificity will produce very long lists and generate responses which cannot be compared between individuals. The Minnesota researchers have repeatedly emphasised a need for an intermediate degree of specificity in the terms used in service-giving and research documents.

- It can be difficult to get some older people to express values or preferences, which they strongly feel, if it concerns something which they find it inconceivable that their services would give them.

- There needs to be some system for identifying which preferences matter most to an individual, perhaps explicit rank-ordering. The problem exists that, owing to the diversity of possible preferences, any instrument for identifying these may list each subject's preferences on a large number of counts. Some of these will be crucial issues for that person, while others are trivial matters. *An instrument needs not only to identify what are a person's preferences but which ones matter most*.

The latter issue is readily illustrated by contrasts between instruments presented in Kane's review. Most comprise lists of statements or topics whose importance to the subject is registered. While in some instruments items are simply either ticked or not, there are others where the importance of an item is rated on a five-point scale or a three-point scale (for example 'Very important', 'somewhat important', 'not important'). Shortcomings of the former approach can be illustrated by the 70 plus items in the Philadelphia Geriatric Center's Preferences for Everyday Life Scale (PGC & VNSNY 1999). So many items are likely to be registered that the instrument may give no guidance as to where staff should concentrate their efforts. Even on scales where graded ratings of the importance of items are included, the sheer number of items prompts doubts about how clearly they can communicate an individual's priorities - c.f. the 54 items in the Preferences for Quality of Life scale (Salmon *et al.* 1998). Devices for communicating each older person's top priorities are essential if these instruments are to influence staff behaviour; the case for ranking, as well as grading ratings, can be clearly seen. Kane's concern to limit the number of items can likewise be understood. The Minnesota researchers' own Values Assessment Protocol (Degenholz *et al.* 1997) comprises only nine items for rating, though each embodies complex meanings.

There is another dimension of contrast among the instruments discussed in Kane's review. They vary in how much they are designed for a specific audience of service staff and essentially comprise instructions to those staff. At one end of this spectrum would be Van Haitsma's adaptation of the Pleasant Events Schedule for people with Alzheimer's disease (Van Haitsma 1999). This comprises a list of 54 activities, all of which can be initiated or arranged by a staff member at a residential unit for people with

Alzheimer's disease. Each item is ticked as to whether a person likes, dislikes or feels neutral towards it. The schedule can thus guide staff concerning their day-to-day work with a person. At the other end of this spectrum would be Gibson's Values Baseline (Gibson 1990) which is intended to promote self-reflection on the part of an older person, not to inform particular service-givers. It includes topics which are outside the common remit of any one service - for instance a person's favourite activities, their desired funeral arrangements or the importance they assign to religious practices during illness. Knowledge of such wider concerns, however, could help staff to provide more sensitive service and, possibly, to arrange help from others in areas with which they could not deal. An issue then may be how far values instruments are centred on the world of older people in general or written to fit common roles and responsibilities of staff who are expected to use the document. Too great an emphasis on the former may produce too little which staff can see as giving them relevant guidance. Too great an emphasis on matching established service-giver roles may rule out constructive challenges to ordinary ways of providing services, since they will obviously reflect conventional views of staff roles. Some instruments described in Kane's review combine enquiries into an older person's general values with some search for their views on how particular services should be given. For instance Doukas and McCullough's Quality of Life Values seeks both a person's general attitudes towards the period around their death and their wishes on specific life-maintenance, pain management and resuscitation issues on which doctors wish guidance (Doukas and McCullough 1991). A new instrument by Kane, designed for Assisted Living schemes, combines a few questions on a person's general outlook with questions linked to design features for older persons' housing schemes (Kane 2000).

As mentioned, the issue on which Kane places greatest emphasis is the need for values instruments to identify both the differing stances which individuals take on each of a range of issues and also which of these issues matter strongly to different individuals. Interest in this subject led the University of Minnesota researchers to test an assessment procedure intended to achieve this. One question was whether a new values assessment procedure could collect the sort of individualised and service-relevant information for which it was designed (Degenholz *et al.* 1997). A second question concerned results from case managers applying this values assessment procedure - did it change the ways in which they worked with their older clients? (Kane *et al.* 1999). Each question can now be considered in detail in turn.

University of Minnesota studies of how preferences and values can be included in case managers' assessments of older people:

(a) Can a values assessment procedure collect potentially useful information?

Degenholz and colleagues (1997) examined what information could be collected through using a specially designed values assessment instrument during assessments and re-assessments or reviews with older people. Some key hopes concerning the instrument were that:

- It could collect information which showed large differences between individuals.
- These would be differences which could inspire care services to respond to different individuals in different ways.
- It could identify not only what were an individual's values and preferences but which of these were most important to an individual.

Reasons cited by the authors for developing this assessment procedure include, alongside belief in the importance of individuals' values, concern that case managers routinely fail to individualise care plans - indeed that they employ "'cookie-cutter' approaches, in which two or three standard service plans are used for virtually all clients regardless of the individual details in the clients' assessments" (Degenholz *et al.* 1997). Furthermore the researchers expected that raising values and preferences during the assessment process would make older people aware of important concerns which they had not clearly recognised.

Design features for the values assessment instrument The values assessment instrument was developed over years. It was informed by dialogue with case managers, by in-depth interviews with older users of services and by tests for validity as pilot versions were shortened to manageable proportions. The following were determined as important design features.

- Questions about values and preference should be a self-contained section of the assessment, rather than scattered throughout it, so as to focus attention.
- Values should be discussed 'at a middle level of detail' to avoid the unwieldy lists which result from too much detail and the uninformative responses which result from too broad, abstract statements.
- It must be short enough for busy case managers to use.
- It should "combine a rating of the strength or importance of each value with open-ended accounts of its actual content".

Content of the values assessment instrument On each of the following set of topics, each older person is asked (a) what is their own preference (b) whether the issue is 'very important' to them, 'somewhat important', or 'not important'.

> *Whether they liked their day routine to be organised in some particular way.* For instance some people may enjoy a very structured, predictable routine - whereas other may relish variety of daily events and lack of timetable.
>
> *Whether there were any particular activities in which they were keen to participate.* This could be either in their home or outside it, like community social events or church activities.
>
> *How they felt about their own family or friends giving them some of the care they needed.* This could involve comment about which individuals they would wish involved.
>
> *Whether it was important to them to have future events to look forward to or goals to achieve.* This could include events like Christmas or the coming of spring.
>
> *How they felt about various aspects of privacy.* One area probed is how much a person wishes to have time on their own, unobserved, and also how much a person is concerned to have company from other people. Another area is how a person would feel about personal care from others like bathing or undressing.

Another is privacy of financial or business affairs, a matter on which some older people are very sensitive.

What price the avoidance of pain or discomfort. This topic concerns how far a person would put up with pain rather than avoid it through restricting their own activities or taking medication which might reduce alertness or ability.

How much a person chooses to take risks when necessary to live more fully, how much were they ready instead to restrict their activities to ensure safety.

What sort of person is desired as a helper with home care. Responses cover personality attributes like friendliness or honesty, areas of competence with tasks, and attributes like age, gender or race.

What makes a place where you live feel like your home. Responses include sense of ownership, being able to receive visitors, freedom to do what one wants.

Testing the values assessment instrument A test of the values assessment instrument was conducted in two case management programmes, which were geographically distant, administratively separate and contrasting locations. The researchers gave case managers substantial practical training both in asking the values assessment questions and in recording client responses verbatim, rather than the case manager's interpretation of the response.

For the test of the instrument, case managers were asked to apply it to all new clients and to all on-going clients who received re-assessments. People with major cognitive impairments were excluded. From the first six months of operation, 779 values assessments from the two sites were examined for the type of information which could be obtained (Degenholz *et al.* 1997).

General conclusions from the test Older users of services generally responded thoughtfully and informatively. The authors comment: "when case managers could be convinced to ask the questions, most clients proved willing to answer them". Responses were thoughtful and informative in that older people proved selective and discriminating in how they used ratings which showed higher importance. There were also conspicuous differences between individuals in the values they affirmed, confirming the worth of this general line of enquiry. While on some topics there were clear majority opinions, the minority with different views nevertheless could be large or could use ratings which showed strong feelings behind their stance. Thus it is worth case managers becoming aware of such minority views. Much information had obvious potential for application in the hands of a case manager. Often the responses showed potential for starting between case manager and client "a dialogue which would shape or reshape" the services given to an individual. The authors comment for instance: "We were struck that the information generated provided a way of identifying clients who had no meaningful activities or projects filling their days and, more important, provided clues to the types of activities that might please the clients or capture their interest."

Such developments might mean expanding services outside common resource limits.

The authors acknowledge that sometimes changes which would suit clients' values may clash with established practices among purchasers and providers and that values assessments thus may be criticised as arousing unrealistic expectations. Since such conflict can be a common milestone on the path to progress, this is not necessarily a drawback – "yesterday's unrealistic expectations can be tomorrow's standard practice" (Degenholz *et al.* 1997).

Some other general conclusions concerning content of the values assessments:

- Differences were apparent between responses of new clients and established clients. The authors see a case for regularly repeating assessments of values and preferences since they seem to change with experience of the service.

- Much training and dialogue with case managers would be required to get case managers to apply this approach faithfully on a routine basis. The main problems encountered were not with service users but with case managers - particularly at one site, which showed markedly lower co-operation.

- On some topics, there were differences between the two services in what were the most commonly expressed preferences.

- Differences between the two services were also apparent in which value topics were rated most important by service users.

- Further differences between the two services were apparent in older people's readiness to apply ratings of high importance per se.

The last three points suggest the complexity of some issues involved. However, it is important to recognise that this presents no necessary problems for the goal of individualised service provision which the values assessment approach seeks to advance. For the latter, all that is necessary is for care managers to design each individual's services to reflect that individual's responses to values assessment questions. Popular care package designs may differ between localities or between different services' clienteles. The reasons for such variations may make interesting further research but these differences between services are not an obstacle.

Some specific findings about older people's values A few more detailed findings suggest something of the wealth of information which the values assessment instrument proved able to collect.

- At both services a values topic which generated highest ratings of importance was a person's stance on whether to take risks in order to live more fully versus limiting one's activities in the interests of safety. At one service a 62% majority favoured the former. At the other, opinions were closely balanced between the two. Responses on this topic were more likely to show ambiguity or contradiction than any other topic. So this is a very charged issue for older people. But they are very divided in their position on it.

- At both services, the values topic which generated lowest ratings of importance was how much a person desired their day to follow an organised routine. At one service a 59% majority preferred a regular structured routine, while the remainder preferred their days to be unstructured and varied. But at the other service the proportions were exactly reversed. Generally this issue of daily routine proved the least charged of the topics examined. But when it did get rated as very important, this came from people who sought a regular structured routine.

- When a person did name particular activities in which they were concerned to maintain participation, very often these were rated as very important. Often they were religious activities.

- Almost everyone showed interest in the personality attributes of helpers like home care staff. Much fewer, a third in total, were also concerned about helpers' proficiency in their specific tasks. One in ten expressed preferences concerning helper characteristics like age, gender or race.

While this study (Degenholz *et al.* 1997) showed conclusively that a values assessment instrument could collect information of potential usefulness to care managers, a key challenge is to demonstrate that care managers can actually use such information to improve the services of individual clients. A second study (Kane *et al.* 1999) addressed this.

The University of Minnesota two-site study of including preferences and values in case managers' assessments of older people:
(b) Can a values assessment procedure affect the behaviour of case managers - in the views of case managers themselves and in the views of clients whose assessments have included a values assessment procedure?

Design of the study As mentioned, this study (Kane *et al.* 1999) examined whether there were actual consequences for older people's services as a result of case managers using the values assessment procedure. It was a controlled study conducted in two case management programmes in one US state, each programme covering a 10 county catchment area. Both programmes had been selected as high quality programmes, both willing and suitable to act as an experimental programme for the values assessment procedure. One programme was then randomly selected for the latter. Eighteen case managers participated in the experimental programme and 21 in the control.

Substantial training was given to the experimental programme in the general ethos of attending and responding to clients' values. The Minnesota researchers emphasise how values assessment procedures are devices for a wider purpose of heightening on-going awareness and discussion of values by both the staff and the clients who complete the instrument. As part of developing case managers' awareness and understanding of clients' values, the researchers took measures like the following.

- They gave staff feedback on what the researchers could glean from the first values assessment documents which staff had completed.

- They held seminars with guest speakers to show staff how care plans could be modified in the light of information on clients' values and preferences.
- They held case conferences on individual clients to discuss how such information might contribute to adjustments to a care plan.

To minimise Hawthorne effects, case managers in the control programme received supplementary training in their standard assessment approach.

For the experimental programme, the values assessment procedure was added to the standard procedures used for assessments and re-assessments or reviews for all clients. Evaluation began six months after the values assessment procedure had become thus included in assessment and review. Evaluation was confined to results from new clients without cognitive impairments. One hundred and fifty eight clients were included in the experimental group and 143 in the control group. Most of the information for evaluation was collected three months after a client's assessment. Information from clients was collected via telephone interviews.

Results - effects of the values assessment

Did clients notice a difference to their assessments? Information was gathered in initial phone interviews three weeks after assessment. Compared to controls, clients in the experimental group were significantly more likely to report that they had discussed their values and interests during assessment or review, that help from family members had been raised and that they had been asked their preferences concerning the amount, type and desired delivery time of home care services and whether they wished a day centre.

Did Care Managers respond differently to clients with whom they had conducted a values assessment? Care managers' own reports on their work showed that those in the experimental group were significantly more likely:

- to rate their work with a client as more intensive than was customary.

- to say they had given service providers specific advice about the timing at which service should be delivered, the sort of worker to assign to a client, or how to work with a client.

Examination of clients' files showed that clients in the experimental group were:

- twice as likely to have had some sort of personal request fulfilled.

- more likely to have information about values and preferences recorded in their care plan.

- more likely to have had some sort of change made to their care package.

- more likely to have a complaint noted.

Did care managers understand clients better as a result of the values assessment? Care managers were asked to predict how their own clients would answer a set of questions on subjects which had been raised by the values

assessment instrument. Comparison with clients' actual views showed that the care managers who had used the values assessment instrument seemed better aware of which clients would choose pain rather than soporific medication, those prepared to risk falling, those who did not want the same routine every day, and those who especially disliked strangers knowing their financial affairs. But on no other counts did they prove to understand their clients any better than did the care managers in the control group. On one subject, recognising which clients liked a structured daily routine, they actually showed less accurate understanding than did the care managers in the control group. So the impact of the values assessment procedure was only limited on this score.

The results incidentally highlighted certain areas where care managers in both groups were particularly likely to misunderstand older people. They greatly under-estimated the importance to them of religion, how much they were concerned with safety and averse to risks, and how much they wished to keep financial affairs private. The values assessment exercise did enhance care managers' understanding concerning financial privacy to some extent. But there was still much room for further improvement.

Did the values assessment procedure affect services after the controlled trial ended? Subsequent to the study, the experimental service incorporated some questions from the values assessment instrument in their routine assessment procedure. More generally, the service appeared to come to recognize the importance of values and preferences as distinct from the 'needs' which had previously been their only focus. An ethics committee to advocate for adherence to values and preferences was set up by the service.

Time costs The values assessment procedure added an average 20 minutes to routine assessment.

Concerning time costs, various actions, which the values assessment procedure appears to have inspired, must have consumed extra staff time, though no information was available on the quantity. For instance time would have been consumed by the more intensive casework reported by case managers in the experimental group and by the extra contacts they reported making with home care providers. There was probably much potential for making yet greater use of information from the values assessment - and this would have consumed yet more time.

Areas were identified where responding to information from the values assessment could conflict with expectations about how case managers should operate. For instance, a case manager might wish to personally brief a client's new home care worker on certain client preferences. But a home care agency would expect instead for case managers to communicate with the agency's own management, who would then communicate themselves with the actual home care worker - with uncertain clarity of transmission. Another example: in assisting a client to make an informed choice of provider a case manager might wish to give the client information about providers. But this contravened conventions that case managers should avoid any possible charge of influencing client decision-making on any commercial matter.

Some 20% of clients who were scheduled to receive values assessments did not in fact do so.

Conclusions which can be drawn from the University of Minnesota studies These two studies thus present evidence that:

- An assessment instrument, which takes around 20 minutes to use with a client, can give a care manager information which highlights important individual differences between older people in what are their values and preferences and in which values and preferences are the most important concerns for an individual.

- This can improve the extent to which care managers strive to design a care package round an older person's values and preferences.

It is important to recognise a point repeatedly made by Kane and Degenholz - that at issue is the creation of a culture of attention and respect for values and preferences, rather than promotion of particular instruments or procedures which address values and preferences. Extensive preliminary training and encouragement to case managers has been emphasised by the Minnesota researchers as necessary to enable values assessment instruments to deliver results in a subtly hostile environment of conventional priorities and habits among case managers. Arguably, once a new culture is developed, service staff may use this new awareness on their own initiative to make ever more enquiries and discoveries concerning older clients' preferences and opportunities for fulfilling them. It is even possible they may achieve more this way than with any values assessment instrument. The latter is a device for raising and focusing staff consciousness towards individuals' values and should not be treated in a ritualistic fashion. Indeed it sounds as though a strong staff orientation towards individuals' values and preferences might produce results without a paper instrument, whereas the reverse may not be true

Possibly the design of a values assessment instrument which thus helps to direct staff attention to individuals' values may be rather different from the design which is useful to a researcher who is studying how staff use the instrument. The former purpose might be best served by a simpler design. It might be helpful to design two separate instruments, rather than attempt a compromise which might limit effectiveness. Concerning an instrument for routine service use, Kane and Degenholz have commented:

> "The intent of a values assessment is not to specify a client's values compared to other clients or to quantify the strength with which these values are held. Rather, the point is to sensitize both the professional and the client to aspects of care which might be important to the client and to pave the way for continuing dialogue on these subjects within families and between client and professional." (Kane and Degenholz 1997a)

Thus the design of a values instrument could be usefully kept separate from the needs of researchers' for instruments to evaluate its usage. The values instrument also needs to be part of a package of measures to promote responsiveness to the individual values of older people if a service culture has become accustomed to ignoring these.

As pointed out by Kane *et al.* (1999), some aspects of responsiveness to individual's values definitely cost extra staff time. At some stage such demands for time can constitute a challenge to the values of the service. Recently Kane (2001) has called for radical re-examination of the values by which older people's support services are judged by public funders. She describes professionals and public funding agencies as prioritising the safety and survival of older people - whereas the latter prioritise quality of living. If service users' safety and survival are made dominant values, responsiveness to individuals' preferences can sound like a luxury, affordable only when staff have time to spare. Kane argues that these current professional priorities are not sacrosanct and could be challenged if a consumer movement sought to "take back the system" (Kane 2001). Something of this sort of culture shift seems to have begun at the experimental service studied by Kane *et al.* (1999). The promotion of individuals' preferences and quality of life concerns may involve friction with the status quo on topics like care managers' dealings with service providers (Kane *et al.* 1999) or the size of their caseloads (Kane and Degenholz 1997b).

Service user preferences in a system for care planning and review in Kensington and Chelsea

Colhoun (1998) developed and evaluated a system for care planning, review and quality monitoring for home care users in a mixed age range home care service in Kensington and Chelsea Social Services in west inner London. This enabled individuals' preferences and values to be entered in three different ways in its documentation. One section enabled each service user to name 'Quality Concerns' - aspects of service which mattered particularly to them or which to them were an index of quality. Another section specified the outcomes to be sought from the service and in each case the people who desired that outcome - be they Social Services staff, service user or family carer. In principle, goals proposed only by the service user could be included here. A third section, which sometimes also communicated a service user's preferences or values, was a 'Personal Profile' about each service user, which was intended to "help providers to deliver a sensitive, individually tailored service". Colhoun's 1998 evaluation of these documents supplies helpful information.

'Quality Concerns'

Quality Concerns were the main way this system promoted service users' preferences or values. Each service user was asked to name aspects of their home care services which especially mattered to them such that, if these were present, the service user would regard their service as good quality. Three different ways of phrasing this question were tested with service users.

(Version 1) "What is most important to you about the quality of services you will receive in your home?"

(Version 2) The same question plus the follow-up question "What do you think makes a 'good' service in your home - and which of these things are most important to you?"

(Version 3) "What do you think makes a good home care service, or good home carer?"

It is noteworthy that this Quality Concerns section seeks only those service user preferences, values or requests which are connected to fairly conventional home care

tasks - and management took steps to try to enforce such limits to how this section was used. Requests for, say, home care staff to assist a client to go on outings were seen as belonging instead to the section of the document dealing with intended outcomes.

Twenty nine care plans were analysed and Quality Concerns were identified in 23 of these. Versions 1 and 2 of the phrasing for the question were used with 13 and 12 service users respectively. Each produced identified Quality Concerns with all but two service users. However Version 3 was finally selected in preference, though it had been tried with only four service users and had proved effective only with two of these.

In total 59 Quality Concerns were named by 23 of the 29 individuals consulted on the subject, while six did not respond. Individuals named between one and four Quality Concerns each. This picture whereby some name multiple items, some one and others none resembles the findings of Patmore (2001a) with samples of home care clients who responded to broadly similar questions asked by senior home care assistants for a staff briefing document and by senior managers in a service review.

Examples of Quality Concerns are as follows. One service user said that home care staff should always "come on time" and "finish the job". For another service user it was that home care staff should know what tasks to do and should "shut the front door when they leave". For another it was that staff should be "adaptable", "'open-minded', for example they do not mind if I have 'accidents'", and "conscious of different problems that may arise if my health deteriorates". For another service user it was that "home care workers should not make you feel old and silly".

The evaluation of the system made recommendations about how to elicit Quality Concerns.

- In future no limit should be sought to the number of concerns entered for an individual - initially a limit of three had been sought.

- Sometimes Quality Concerns were being entered through verbatim quotes from a service user, which were in fact mixing together two or more separate concerns. In future, the care managers who undertook these reviews should take care to enter them as separate items, so that whether each had been fulfilled could be considered separately.

- Further probing would be needed with certain Quality Concern entries if staff were to be able to draw from them any guidance for action. One example was a request "that the service continues to be perfect". In such a case, the evaluation commented, care managers should keep asking what made the service perfect until the service user said something which showed staff what they should do or keep doing in order to maintain such satisfaction.

- Some Quality Concern entries could not be fulfilled because they conflicted with rules governing the service. For instance one service user sought "some facility to be able to decline certain workers and have this kept private". This was not permitted in this service. The evaluation recommended that no concerns or requests which conflicted with the services rules or principles should be entered.

(The latter issue was also noted by Patmore (2001a) but a different response proposed. Enquiries about service user preferences or requests were seen as often leading service users' attention to types of help which the service did not normally give. It was suggested that requests which could not be granted should still be recorded, though other requests or concerns should be also asked for. Service reviews could periodically reflect on records of unmet requests, consider whether there were any ways in which changes could be made to policy - or whether some other response were appropriate. In the case of a request to avoid certain staff members, for instance, were the records of one team to show many more such requests than other teams, this could helpfully alert managers to a problem. They could then explore the reasons why some workers appeared unpopular.)

Kane's advice to avoid precise semantic classifications (Kane 2000), mentioned earlier, may be pertinent to disagreements, which arose during the Kensington project, as to which parts of the document different forms of service user comment should be entered in. The managers of the quality system appeared very concerned to preserve semantic differences between Quality Concerns and statements of goals or intended outcomes. This occasioned some conflict with care managers who preferred to enter verbatim entries from service users even when these ignored this distinction. Perhaps it may not be worth pursuing semantic distinctions unless there is evidence that the benefits that this is bringing can outweigh the conflicts it generates.

Likewise the Kensington evaluation report includes inadvertent illustration of Kane's cautions about aggregating statements of individuals' values (Kane 2000), which were mentioned earlier. There are instances where Quality Concerns are categorised in ways which abstract their meaning. The category "appropriate professionalism" is used to label a set of Quality Concerns as diverse as "a home care worker that doesn't complain" and "home care workers should not make you feel old and silly". For purposes like briefing staff or devising training, you need the actual messages from service users; a category label conveys little.

It proved possible to judge during service reviews whether Quality Concerns had been met, though substantially fewer were thus evaluated than had been hoped. Judgement was made solely by service users and their family carers - whereas both care managers and service users made separate ratings where the outcomes of services was concerned.

Total Quality Concerns which were evaluated	22
Completely met	8
Met to a large extent	11
Met to a some extent	3
Not met at all	0

Some lessons were drawn from evaluation of this process for future application.

- Care managers should consistently ask users their reasons for the ratings they make, like those just cited, and should enter these reasons in the review documents.

- Where a Quality Concern relates only to one of a number of providers who serve a client, this should be stated in the care plan.

- If a Quality Concern applies to all providers who serve a client, a general comment from the client should be sought initially rather than asking about each provider in turn.

- Care managers should conduct these reviews without the providers present.

An extra feature of the documentation was a rating of overall satisfaction on a five-point scale, coupled with request for explanation. It appears that in at least one case this may have usefully identified a service user's dissatisfaction with an unexpected change to their service which had occurred since Quality Concerns were named. This illustrates the value of complementing more specific enquiries with such a question. The evaluation makes a general comment about the documentation often failing to be updated to reflect changes to services - some such problems are probably unavoidable in any system. This general rating of satisfaction, if combined with space for explanation, may provide opportunity for service users to make comments on issues which have arisen only recently or which documentation has not otherwise anticipated.

Intended outcomes

Under the Kensington system, service users' individual values and preferences could also feature in the naming of goals and intended outcomes in the Care Plan. Sixty per cent of the intended outcomes listed were named by service users themselves as outcomes they desired. The categories of intended outcomes cited in the report do not differ very evidently from those commonly sought by social services; individuals' values do not seem evident. The evaluation comments: "Outcomes set were largely related to day-to-day functional needs, with other domains seldom ventured into". Generally service users and care managers agreed in their ratings of outcomes though there were two clear instances (out of 98) where they disagreed substantially on whether a particular outcome had been achieved. The documentation proved able to supply detail which explained the reasons for such disagreements.

'Personal Profile'

A final element in the documentation was the 'Personal Profile' described earlier. While this was not covered by the evaluation, examples are supplied which show that sometimes at least this document communicated service user values and preferences like those to which the Minnesota researchers draw attention. This document appears to serve similar purposes to the home care briefing document described by Patmore (2000), Patmore (2001a) and, in detail, Patmore (2001b). But it is much longer and less structured. Examples of the completed Kensington document suggest additional topics which might be added to Patmore's structured format - like preferences concerning food, any favourite subjects of conversation, and attitudes to different parts of their daily routine.

Timewise, the evaluation concluded that "the project system at the very least demands no more time than the usual system". However it seems clear that there were plenty of

instances when the various documents were not completed as intended, but this may not matter greatly.

Portsmouth Social Services' exploration of approaches for enhancing older service users' control or direction of their home care services

Clark and Spafford evaluated a nine month long experiment in modifying home care services for selected older people (Clark and Spafford 2001). A prime purpose for the scheme was to investigate developments which would be necessary to subsequently offer older people the option of Direct Payments to employ their own home care staff. Other purposes included a general wish to find ways of giving older people more choice and control over their support services in response to research findings about their aspirations - for instance Clark *et al.* (1998).

During initial assessments or reviews, care managers were instructed to offer an experimental scheme to those older people who seemed able to use it. During a nine month period, 31 older people chose to engage with the new scheme. For each participant in the new scheme, care managers assessed what number of hours of home care support the person needed. Each participant could then choose one of the following three options for how they received this entitlement to service.

Simulated Direct Payments scheme A participant's hours of service could be supplied by a personal worker engaged on terms similar to a Direct Payments worker. The service user was expected to find their personal worker from people they knew, by word of mouth or by advertising, and also to brief them on services required. However, since this was only a simulation of a Direct Payments scheme, the Local Authority employed the worker and organised interview, police checks, training and payment.

Own choice of independent sector agency A weekly cash entitlement was calculated for each participant by multiplying the hours they had been assessed as needing by an average independent sector hourly home care charge. Participants could then choose service from whichever locally accredited agencies they wished - up to the limit of this cash entitlement. This allowed participants to choose, if they wished, fewer hours of service from more expensive agencies if they valued the quality of the latter. They could choose service at whatever times they could obtain from the market.

More flexible use of social services own home care service Participants could seek to contract their assessed number of hours from the social services home care service for whatever times and purposes they chose - if the service could supply this.

A general aim was that all three arrangements should offer service users greater personal influence over what times service was delivered and over what staff actually did during each visit. Within a three month limit, service users were allowed to save up their entitled hours of service so that they could use these when they specially needed them. An important difference from conventional home care arrangements was that service users could ask their workers directly for changes in what they did and when they did it, without such requests sometimes having to be first approved by care managers. The main limits were an individual's ceiling of hours and the capacity of a provider to fulfill requests. However there seems to have been a 'grey area' concerning whether service users could obtain types of service, like housecleaning, which had not

been envisaged when they were assessed for the scheme by a care manager. It seems likely that this ended up being treated somewhat differently in different cases.

During the nine months studied, 31 older people participated in the scheme. Of these, there were seven who chose the simulated Direct Payments scheme, 20 who chose the independent sector option, and four who chose the social services home care service. Evaluation of the scheme rested on interviews with different stakeholder groups. Direct records of service-giving were not used.

Useful lessons from the experimental scheme Much of the focus of the evaluation necessarily concerns lessons specific to local extension of Direct Payments to people aged over 65 years. Some general lessons are as follows.

- Some older people can feel daunted by new arrangements which, whatever gains they promise, sound as though they may burden one with having to make more decisions and organise one's services oneself. Also, while some older people resented care managers' control of their services, there were others who actually feared loss of care managers' presence as intermediaries who could address any problems with the provider on their behalf. Reservations about managing services for oneself resulted in people declining to participate and in the relatively small number who would try the simulated Direct Payments option, the option which required most from the service user. In the Direct Payments option some older people encountered difficulties in finding a worker: They feared recruiting a stranger via advertising but, if one had few remaining social connections, it was hard to find a suitable person any other way.

- In consequence a case emerges for giving how older people greater information, support and time for decision-making concerning such schemes and more help to find Direct Payments workers.

- The scheme had anticipated that paperwork might cause problems for its users and had carefully streamlined required paperwork. These measures proved generally successful.

- Whatever the reservations among older people about Direct Payments, those who took this option probably obtained the most satisfying service according to the evaluation, though information was not conclusive. The core reason seemed to be the forming of a relationship with a single, chosen worker, who got to know the service user's circumstances very well and, moreover, was more readily available than home care staff with competing commitments to many other clients.

- Free choice of independent agency, the second option, did not result in any 'shopping around' by those who chose this. Rather, they stayed with agencies who already served them on the grounds that they lacked the information needed to make reasoned choices.

- All but one independent sector provider found it hard to provide service flexibly at the times when scheme users requested it. All found it hard both to be flexible and to supply a worker whom a service user knew well.

- Social services own home care service also found it hard to combine flexibility of timing with continuity of staff. Only four people took this option and there was no evidence that it resulted in changes to their services.

- There were clear signs that, if another family member administers or directs any of these options on behalf of an older person, the latter risks gaining little choice or control. As many as 13 of the 20 care packages with independent sector agencies were managed by relatives of the service user, so this proved an important issue.

- Hospital-based care managers opposed presenting people with the option of alternative services while they were still in hospital (Clark and Spafford 2002). They felt that it should wait until they were well settled back in their own homes. It would be difficult, they felt, for older people to engage with the scheme when they were still feeling ill, were uncertain about how well they would recover, and when they were receiving much competing information from professionals in connection with their discharge.

- Potential for conflict exists between care managers, as people who ensure that social services money is spent only on meeting particular needs (for instance nutrition rather than a thoroughly clean home) and any scheme which might allow service users to change the way such money is used. Some care managers worried that the scheme might allow a fortunate few to circumvent the rationing of funding for older people, so that they might obtain house-cleaning contrary to policy, for instance. Some care managers felt that the scheme removed an important part of their role.

The following conclusions could be drawn.

- The high satisfaction with Direct Payments is indeed notable – for those few who could be persuaded to try them.

- Also notable is the apparent importance of a single worker, who gets to know an older person's circumstances very well, in occasioning such satisfaction. This can be possible within conventional home care too. Should the latter strive to arrange provision through a single worker as much as possible?

- Older people's wariness concerning more self-managed ways of obtaining home care highlights the potential usefulness of SPRU's project. The latter intends to explore means for enhancing choice and control which require less autonomy, self-direction or risk-taking than the options offered in the Portsmouth scheme. The latter suggests that many older people might prefer such a more sheltered route to enhancing choice and control. It is important to keep in mind these older people's reservations. Perhaps the SPRU scheme should deliberately seek to complement Direct Payments. Perhaps it should be shaped as an alternative, sheltered route to greater choice and control for people who are worried by the leap to actually purchasing their own services.

- Attention needs to be paid to new, constructive roles for care managers within the envisaged SPRU scheme. The latter might conceivably reduce their role, just like in the Portsmouth scheme, and devolve some of their powers to service users and provider staff. Thought needs to be given to ways in which care managers could be positively involved.

Miscellaneous additional useful messages concerning service user requests from the literature search

Hardy *et al.* (1999) interviewed UK domiciliary service users, family carers and care managers concerning consultation, choice and requests in the assessment and care management process. Care managers believed that what services a client received was largely determined by what was available or what could be afforded at the time of assessment, rather than what either client or care manager thought appropriate. Aware of such realities, care managers could be reluctant to encourage clients to clearly voice choices during assessment since there was such a high risk that their request might not be fulfilled and the client left disappointed. Service users conveyed a corresponding feeling of having only limited involvement in the assessment process, for instance simply being told what was on offer and having some opportunity to comment. Among users of home care services "… few had been offered a choice of care workers or the particular elements and timing of services at the care planning stage. They had been expected, instead, to define their needs in terms of what was on offer. As one woman said, when asked if she chose the timing of her local authority cleaning service: 'No, not really, I've sort of had to fit in. Monday was the only day, I had no choice for that.' ... For the majority of users and carers, participation in the design of their care package was limited to the 'negative' choice of refusing the providers and services offered" (Hardy *et al.* 1999). Service users often appeared to feel inhibited from making either requests or complaints through feelings that they should be grateful for what they got or that social services could not afford to give more.

Another factor which inhibited requests was that it was only after a person began to receive their care package that they could judge what adjustments they needed to it. Requests for adjustments could be made then only if the care manager remained involved with the case. But if the care manager had terminated their own involvement it could prove hard to obtain such adjustments.

Reviews by care managers seemed to focus on cases where independent sector services had been commissioned and to ignore those where services were wholly provided by staff employed by social services.

Older service users' reluctance to voice requests for adjustments to home care services was also noted by Woodruff and Applebaum (1996). They comment on a variety of approaches to discovering service users' views. A highly successful but very time intensive approach was for researchers to simply spend time with older service users on repeated visits over two to eight weeks - chatting, helping them with tasks inside and outside the home and generally observing their lives. Such observation showed that older people could encounter faulty services, which definitely troubled them, yet they held back complaints or requests to workers or agencies. Dependence on workers seemed one factor which inhibited complaints. Sometimes desire to protect a worker from managers also seemed an influence.

People who were especially troubled by shortcomings of their services were those who had least in the way of relatives or friends. Other older people could actually draw on relatives or friends to help in ways which home care staff were failing to provide. Sinclair *et al.* (2000) also note this phenomenon. They found that in some places neighbours or nearby relatives might periodically give home care service users later bedtimes than those offered by the home care service so that they could stay up for a favourite TV programme. Noteworthy is the wide variation between communities in whether older people have strong networks of informal helpers – the latter is more common in communities with little migration in either direction (Wenger 1992). In contrast, particularly many isolated widowed older people are found in seaside retirement communities, to which older couples have migrated, leaving their networks behind (Wenger & Tucker 2002).

Woodruff and Applebaum conclude that postal surveys are the least effective means for identifying older people's true concerns about quality aspects of their services, while face-to-face interviews or extended informal observation obtain most information.

Telephone interviews obtain a moderate level of information, according to Woodruff and Applebaum. Telephone communications merit particular attention since in the UK they are a common means whereby both care managers and home care provider managers check with older clients whether new service arrangements are experienced as satisfactory. In Australia Lewin (1998) compared face-to-face interviews and telephone interviews as a means for assessing the satisfaction of home care clients with services. Older people tended to communicate criticisms more readily in face-to-face interviews, though the types of criticisms gathered were similar with both methods. However telephone contacts seemed clearly unsuitable for communicating with people in poor health. Further discussion about the relative merits of home interviews, phone interviews, group discussion and postal surveys for obtaining older people's views on their services can be found in Patmore *et al.* (2000). (In essence, home interviews seem the most widely liked and practicable method and postal surveys the least, while phone interviews suit some older people but definitely not others.)

It is possible to gain more information about older people's concerns re the quality of their home care services if specific topics are raised, according to Woodruff and Applebaum (1996). Using telephone interviews, they found that, while 95% of respondents affirmed satisfaction when asked in general terms, specific questions about workers' punctuality, courtesy or notification about changes showed that 20% to 30% were dissatisfied on some issues. They recommend using sets of specific questions to prompt responses if seeking to elicit complaints, regrets, or requests for change among older home care users.

Another approach for eliciting such comment is suggested by Williams and Keating (1998). They argue that older users of home care often have no yardstick or standards of what it is reasonable for them to expect so they do not know when it is reasonable to complain or request something extra. Their responses may be different if at the outset they receive written information about what to expect in terms of, say, margins for punctuality or how long their workers should stay.

Two studies attempted to identify a general hierarchy of priorities and values among older people – the sort of approach which Kane and colleagues caution against. Robertson (1995) used some structured exercises in consultations with four contrasting groups of older people - one recruited from a disability resource centre, another from a 'learning in later life' programme, and two from District Nurse caseloads which included people with marked mobility and health problems.

- People sometimes did not rate an issue as important for older people if they already received services which addressed it very well. For instance the group from the disability resource centre placed less emphasis on mobility and transport than other groups because they already enjoyed an excellent transport scheme via their resource centre.

- The consultations tried to get each group to draw up a hierarchy of needs or priorities among older people. To an extent some such common values were agreed. For instance having a telephone, being sufficiently warm and receiving good health care were widely rated as primary priorities for older people. Less urgent items of value would be home care services which included hairdressing, escorted shopping for clothes, help to revive old interests or hobbies, or companionship from home care staff if desired. Could problems arise if schemes to enhance home care try to offer services like the latter to people for whom more fundamental needs are unmet? This is certainly a point to remember.

- Despite a structure to the consultations which promoted collective statements of older people's values, individual differences in older people's values sometimes prevailed - in line with the approach of Kane and Degenholz. Robertson comments: "For some individuals certain needs were essential or high in priority - even if this view was not shared by others. Such a need might, for example, be spiritual: for access to a church or to be able to have communion at home each Sunday. Perhaps a participant was burdened by the maintenance of a house and felt acutely worried about a leaking roof or poor plumbing: a need to help with this would be uppermost."

A study of 180 home care users in Sweden also sought to identify a hierarchy of priorities among service users - but in this case specifically concerning quality aspects of home care services (Edebalk *et al.* 1995). This seems a type of exercise which requires caution, bearing in mind Kane's (2000) warning: "'Average preferences' for a group may be statistical artefacts that end up reflecting no person's views." The Swedish study did formulate a hierarchy of values. While the study does not discuss how widely individual home care users differed on these values, it does reveal much variation between sub-groups of home care users. For instance rankings of the importance of different aspects of service (for example whether it is more important that a home care worker be punctual or careful or friendly) could differ between older people and younger people, between town and countryside, between men and women and between groups of people with differing occupational histories. This is reminiscent of the intriguing differences in common values noted by Degenholz *et al.* (1997) between interviewees at different research sites. This sort of variation could be perceived to add to the case for an individual-centred approach to home care quality. If even such large categories differ from each other, what is the point, some might wonder, in calculating a notional common hierarchy of values among all home care users.

Finally, the literature search identified two further studies which each contribute perhaps an idea or two concerning person-centred, client-led home care services.
Eales *et al.* (2001) interviewed residents of two contrasting types of innovative systems for residential care in Canada. One comprised self-contained units of supported accommodation for 30 older people and was strong on both privacy and opportunity for organised activities. The other model offered accommodation in the home of a family to between one and four older people per home. The family were paid to supply social contact as well as care. This model was strong on opportunity for relationships. Research interviews attended closely to what residents sought from a home. Individuals were found to differ widely concerning the latter. Large differences between the social aspects of the two models of home meant that contentment could hinge on whether a person moved to the one which suited them, rather than what was available. A case was made for greater availability of varieties of supported housing to enable such matching. Considering home care services, could this suggest that some provider agencies could helpfully cultivate differences in what they offer? Quite often, when a social services department has many providers to choose from, providers compete to provide a similar service. But might there be room for some independent sector agencies to cultivate styles of work or relating which appeal to different service users?

Soskis (1997) studied a group of homecare clients - half of them older people, half people with AIDS - who were completing advance directives about how they wished to be treated around the time of death. Some ideas from this study are as follows:

- Is there a case for including this practice within information-collection on values and preferences among older home care clients? Plainly selectivity and sensitivity would be needed, but are there not some situations where it would bring benefits? As Soskis comments, providing terminal care at home is becoming more common.

- Many requests were made in this study which were highly individual and did not match any issues in standard enquiries on the subject. This reminds us that open-ended questions lie at the heart of enquiry into values and preferences.

- Participants said they appreciated receiving a written first draft of their requests, written after an initial discussion of the issue. After they had reflected on this on their own, a modified version could be finalised with the service. Plainly the value of such a two-drafts process may reflect the particular situation of imminent death. But might it be worth trying a two-drafts process in other situations where service users are consulted about preferences?

- Soskis recommends that no professional introduces advance directives for the period around death without having experienced writing such an advance directive for themselves. Testing a service user preferences/requests procedure on oneself has obvious importance where discussion of death is concerned. But could this apply to other situations too?

5. CONCLUSIONS

There is ample evidence that older people do differ substantially in their values and preferences – and in ways which have practical relevance to services. There is evidence too that they can often readily discuss their values and preferences with social care staff and can compare, rate and rank the importance of different preferences. Standard forms and procedures can be devised whereby service staff can gain such information from older people. Social care staff can be influenced by information on older people's preferences so that, sometimes at least, they can adjust services to suit individuals. On all these counts there is clear support for the practicability of a person-centred approach to home care, which seeks to adapt to the values and preferences of each individual.

But what no-one has yet examined in any depth is the extent to which information thus communicated by older service users can be translated into adjustments to their services which bring *truly substantial* benefits to service users. SPRU's new project on flexible person-centred home care for older people must address this.

From the many issues raised by the literature reviewed, perhaps a few conclusions can be drawn for the benefit of people seeking to develop person-centred services.

Documents and procedures need to be kept simple

Broad, open-ended questions need to be at the heart of instruments and procedures for discovering older people's values and preferences. This is essential to reach concerns which an interviewer has not conceived of. Could it be that *only* very global open-ended questions should be used? Kane's review of methods used (Kane 2000) showed how a multitude of interesting topics exist where specific questions and ratings could be added as prompts. These can generate instruments with far too many questions for the staff time available to ask them and which promise much more information than staff can use.

Alongside global open-ended questions about a service user's preferences and requests, there is certainly an attractive case for adding questions on some standard topics where service staff are know to often miss important differences between individuals - like older people's readiness to take risks with their own physical safety, the areas where privacy is most important to a person, and religious concerns. Other standard topics might include a person's feelings about the timing and the reliability of home care visits, the number of different staff who provide these, and their relationship with these workers.

But can there be room for very much more? Is there in fact room even for all of these? People developing documents and procedures for person-centred approaches will need to examine this carefully. At the heart of enquiry into an individual's values and preferences must be space for open questions whereby an individual can articulate types of concern which have never occurred to the researcher who designed the instrument. More structured questions must not get in the way of this. Instruments had maybe better err on the side of simplicity and brevity.

It is also important to recall Kane's warnings against attempting detailed definitions or

classifications of service user ‘values’ or ‘preferences’ (Kane 2000). Unproductive semantic argument may result. It has proved possible to conduct effective investigations without elaborate definitions of terms.

Not just documents and procedures, but a whole new way of thinking
Kane repeatedly points out that instrument and procedures are only one component in the promotion of the values of individual service users. An essential accompaniment is to promote among service-givers a general culture of interest and respect for older people’s individual values and preferences. Once developed, such a culture may produce changes to services without a paper instrument to formally discover customers’ values. In contrast, the instrument on its own, without supporting values among staff, seems unlikely to make major progress. Kane and her colleagues found it necessary to invest much effort in consciousness-raising activities concerning individuals’ values – via seminars and case-conferences for care managers for instance. They convey that some conflict can be expected with conventional priorities and habits among care managers, however well a scheme is initially greeted. If this stage is passed and a new culture develops, staff may on their own initiative make discoveries concerning older clients’ preferences and opportunities for fulfilling them, independent of any values assessment instrument.

Is a single main home care worker the key? A subject for investigation
Some studies reviewed here have pointed to another factor which *might* produce home care which is well attuned to the values and preferences of each customer, independent of any values assessment instrument or procedures. This is when a customer’s home care is supplied through only one major worker, plus a carefully limited number of back-up staff. Commonsense suggests that, if one worker supplies much of a client’s care, that worker will become well placed to learn and respond to many different client preferences, small as well as large. There seem many benefits from such arrangements and the major relationships between home care worker and client which develop as a result (Schmid and Nirel 1995, Sinclair *et al.* 2000, Clark and Spafford 2001, Olsson and Ingvad 2001). Direct Payments arrangements are a pronounced example, as described by Clark and Spafford (2001).

But how reliably do such benefits materialise? Are there pre-conditions for ‘one major home-carer’ arrangements producing them? For instance it may require that the worker be given particular briefing, training or discretion to make decisions jointly with the customer and enough time to simply talk to a customer for a relationship to develop. It may require particular attributes on the part of the worker. Attention is also needed to the disadvantages of relying heavily on a single main service giver – like replacing that worker when they are ill, on holiday or change job, finding enough staff who suit such a role, and the difficulty of detecting abuse by the main worker when other staff have little contact with their customers. Since people receiving multiple daily visits must receive service from more than one worker, issues include what upper number limit of regular workers per client can still bring the benefits associated with continuity by Olsson and Ingvad (2001). There seems a strong case for investigating these various aspects of organising home care via a single main worker per customer.

Needed – a system which is much easier for older people than Direct Payments
Current progress nationally in services for older people includes measures to enhance

their choice and influence over services; older people's recent access to Direct Payments should assist this. But a study reviewed here suggests that many older people will avoid participation in Direct Payments because they see their own role in it as difficult and burdensome (Clark and Spafford 2001). Accordingly it is helpful to develop less challenging, user-friendly arrangements for enhancing older people's choice and influence over their home care, which can appeal to people who might avoid Direct Payments.

Both purchasers and providers should receive attention

To develop home care services which are responsive to older people's values and preferences always requires attention both to service providers and to Care Managers, the service purchasers. Plainly ability to be responsive to a large part depends on providers. But sometimes Care Managers can be a dominating influence on how providers are required to treat service user requests. The role of Care Managers can vary widely in degree of prescriptiveness (Sinclair *et al.* 2000). Their influence may increase as independent sector agencies provide a larger proportion of home care. Even when a scheme is focussed on providers, indeed especially when a scheme aims to reduce the role of Care Managers, it is vital to address the role of Care Managers in the system overall. The Portsmouth experiment in alternative approaches to home care (Clark and Spafford 2001) is a case in point. Kane (2000) has pointed to a need for dialogue with service purchasers on areas where their priorities differ from those of service users. Possibly this dialogue may need sometimes to be conducted at quite a senior level. If as Kane says, respect for older people's values and preferences entails a whole new way of thinking, it is clearly important that service commissioners be involved as well as providers.

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Appendix

SPRU'S RESEARCH PROJECT ON FLEXIBLE, PERSON-CENTRED HOME CARE FOR OLDER PEOPLE

This project began in October 2001and finishes late 2004. Its origins and intentions have been described in detail in Section 1 of this report, 'Reasons for this literature search and the research project of which it is part'.

In short, it aims to make practical recommendations about teamwork models, procedures, policies and resources which enable home care to respond flexibly, yet within affordable resources, to heartfelt personal priorities expressed by older service users. The research is funded by the Department of Health.

The project comprises three stages and publications from each stage are made available on:

http://www.york.ac.uk/inst/spru/research/summs/homecare.htm

Scroll to 'York Home Care Internet Publications' at the end.

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