

Terms of Engagement

Engaging older people
in the development
of community services

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Summary

- Major changes are taking place in the welfare state and in the way that health and social services provide for older people
- This paper makes a case for *engaging with* older people about their experience of life in general, as well as about their experience of services
- *Engagement* means seeking out older people and giving them a chance to say what they think, reflecting on their experience and drawing lessons from it, agreeing action to bring about improvement, taking action and ensuring that the process of engagement continues
- The paper describes one approach to engagement with older people in Kirkby, Merseyside, and the lessons which can be drawn from the work.
- The Kirkby work showed that community care services cannot be seen in isolation from other aspects of people's lives. Older people had a range of concerns about life in their community, as well as specific comments about health and social services
- The project demonstrated that productive working relationships can be established between older people and professionals. These go beyond traditional forms of user representation on working groups, enabling older people to play an active part in evaluating current provision and influencing future service development
- This type of approach could make a useful contribution at both local and national levels in ensuring that policy and practice reflect the experience of older people and their requirements for services and community life

ENGAGEMENT?

This working paper is about *engaging with* older people around the development of community services. By this I mean collaborating in a way which takes people's views seriously and acts upon them. This is discussed later.

AIMS OF THIS PAPER

This working paper sets out to do three things:

1. Make a case for *engaging with* older people to find out about their lives and the support they may require as they become ill or frail and to develop services in line with their experience and aspirations
2. Describe an approach to engaging with older people which may be helpful to groups of older people and professionals. This approach is based on some pilot work carried out in Kirkby, Merseyside
3. Suggest lessons from the experience in Kirkby, and thoughts about how this approach might be developed in the future

Background – the case for engaging with older people

There are a number of reasons why engaging with older people is becoming an important and relevant issue. There have been major changes in the welfare state in recent years and more are on the horizon. We have seen a significant shift from long-term hospital care for older people and more emphasis on care at home and residential care in local authority or independent sector homes. In addition to moves away from long term hospital care, current policies also seek to limit care in residential or nursing homes. Health and social care policies place great emphasis on care at home for people who have chronic illnesses or disabilities (mainly elderly people). Even acute episodes of ill health or injury are expected to be dealt with extremely quickly in hospitals, with aftercare provided in the home. Many of the changes in the welfare state currently under discussion (means testing, charges, changes in benefits, etc.) are likely to have major implications for older people and there is a strong case for engaging with them about the impact of such changes.

As people live longer and the birth rate declines, older people become an increasing proportion of our population. Health and social care for older people is a major part of both health and social services budgets. It therefore makes a great deal of sense to take this 'client group' seriously and to ensure that money spent on public services really does match the requirements of those served.

More attention is now being paid to the rights of older people. Local pensioners' groups and national organisations representing older people are increasingly fighting for the voice of older people to be heard and taken seriously. Newspapers have highlighted concerns about the quality of care which some older people receive.

The result is an increasing recognition that older people are 'citizens', 'voters' and 'consumers' and can expect to be taken seriously. This includes consulting them in the planning of the services they receive. Older people expect to be taken seriously as consumers of services and for services to learn from their experience and adapt. It is also true that many of us in middle age can see our time as 'senior citizens' fast approaching and have a vested interest in ensuring that when our time comes services are in place which take our views seriously.

The new government has placed emphasis on citizenship and has indicated its willingness to consult through focus groups, citizens' juries and other forms of group consultation. It is a simple extension of this idea to suggest that older people, as citizens and consumers of services, should be consulted about issues which affect their lives and well-being.

The marketplace is not the complete answer to the effective running of health and social services. Indeed, recent announcements have suggested that at least some of the internal market is to be dismantled, which will require alternative ways of assessing and planning priorities.

Another recent trend is an increasing awareness of public health. Despite the current emphasis on food safety (especially the BSE debate), attention is also being given to the conditions in which people live. Agencies are striving to work with local communities and efforts are being made, for example, to bring together people living on housing estates to discuss their future and to accept some responsibility for the conditions in which they live. Initiatives such as the Social Exclusion Unit and Welfare to Work are a positive attempt to find ways of assisting disabled and disadvantaged people to take a more positive role as citizens.

These policies suggest that it is both timely and relevant to think about *engaging with* older people.

This report is also about engaging with people *about their lives*, not just about the services they receive. In this project we began by wanting to find out more about older people's experiences of home support services. However, it soon became clear to us that people's experience and perception of services is closely linked to their overall experience of life. Many older people rely on family members for a great deal of their support and it makes sense for services to take this into account. The quality of local facilities and services (for example leisure, transport, the police) has a major influence on people's experience of life and the help and support they require from those services.

We therefore decided to *engage with* people about their experience of life in general and to look beyond their experience of health and social care support in isolation.

I have deliberately used the term *engage with* to make an important point. Of course we listen to the views of older people. Health and local authorities have consultation sessions. They sometimes send out questionnaires or go out and interview people. Some general practices carry out health checks on over-75s. GPs, nurses, health visitors, doctors, social workers, housing officials, and many other professionals come into daily contact with older people and hear what they have to say. Those of us with elderly parents, friends and neighbours listen to them. But do we always engage with them?

I use the term *engaging with* to mean a combination of things:

- seeking out older people and giving them a chance to say what they think. This includes making contact with people who are not articulate, or who may have problems with speech, but who nevertheless have important views and experiences;
- reflecting on people's experience and drawing lessons from it;
- agreeing action to bring about improvements;
- taking action;
- ensuring that the process of engagement continues.

So *engaging with* is much more than seeking people's views. It is about learning from what they say and taking action to improve things.

An approach to engaging with older people

This part of the paper suggests one way in which a group of people can engage locally with older people living at home and needing support. It is based on work which the King's Fund carried out in collaboration with health, social services and others in Kirkby, Merseyside.

I do not suggest that this is the only approach to *engaging with* people. It simply sets out one possible way of making a start. Many others have worked with older people and listened to their views and some of this work is referred to in Appendix 1.

Here, I set out an approach and show how it worked in Kirkby. There are also examples of things which did not work well, and I have drawn lessons from them.

The approach

There are eight steps:

1. Identify the reasons for engaging with people
2. Identify people to work with
3. Set up joint working
4. Agree an approach to engaging with people
5. Identify people to engage with and arrange visits

6. Learn from people's experience
7. Translate lessons into practice
8. Keep up the momentum

1. Identify the reasons for engaging with people

There is little point listening to people without a clear idea why you are doing so. The process here is based on an assumption that we want to learn from the experience of older people and are prepared to consider changes in the way services are organised. If there is no commitment to change, there may be no point in starting. Sometimes, however, people want to collect information to make a case for action.

IN KIRKBY

We started with the Director of Social Services, who was keen that his department would work with health and others to find ways to improve services to older people. He set up a meeting with a number of people who had an interest in developing the services that older people receive at home. People who attended the meeting were enthusiastic about the project which would help them to learn about older people living at home, and encourage them to think about future developments. They were keen that this was to be a joint project, involving a number of organisations as well as older people.

2. Identify people to work with

You will need to find a group of people to work with. This should include both people from various service organisations and older people who have an interest in working for change. It helps to have some senior people involved. They are often in a better position to ensure that things happen, and their support for the work can be invaluable. If you are part of a group of older people who are taking the initiative, you will need to work hard to interest and involve some professionals and conversely, if the initiative comes from professionals, you will need to work hard to interest and involve some older people. People will want some idea of the commitment involved. This is likely to include:

- attending meetings to plan the work;
- spending time with older people in the community;
- spending time working out the lessons learned;
- action planning and progress chasing.

Have an overall timescale in mind, say six months or a year.

IN KIRKBY

We identified a project group who were committed to the work. Initially this included:

- two people who attended a social services resource centre for older people;
- an assistant director of social services (who chaired the group);
- a social worker who acted as care manager for older people;
- the manager from the resource centre (who also managed home care services);
- a support worker from the resource centre;
- the locality manager from the community NHS trust
- a community nurse clinical supervisor;
- three people from the health authority, with an interest in community support services;
- a community health development worker;
- someone from the local council for voluntary services;
- someone from Age Concern;
- a project consultant from the King's Fund.

This group met and agreed an overall action plan.

We soon realised that we had fallen into the trap of packing the group with professionals without giving enough thought to ensuring that older people were fully represented. The two people from the resource centre made valuable contributions, but their voices were 'drowned' by the large number of professionals. Sadly, one of these two became ill, and was unable to continue to attend.

Fortunately, some members had good links with groups of older people in the locality. They spent time discussing the project with them and eventually recruited some seven older people. Many of these were associated with the local Retired Members Association, an organisation of ex-Trade Unionists who provided support and campaigned for a better deal for older people.

3. Set up joint working

It takes time and commitment to achieve effective joint working. People from different professional backgrounds often speak different languages and use different jargon. This can be even more confusing to people inexperienced in professional meetings. There are often 'hidden agendas', for example, where one agency wants to save money by passing work to another.

For older people, attending meetings and playing by the 'professional' rules can be a daunting experience. The same thing can happen in reverse, when professionals attend meetings organised by older people.

It takes time and patience for a mixed group to gel. People must learn to respect each other and understand their different backgrounds. Getting on with a practical task and sharing the workload can often be a good way of overcoming barriers. A neutral venue for meetings (not part of one service organisation) can also help.

The group will need to agree its overall programme of work and a good starting point could be the following:

- Identify people to engage with;
- Agree an approach to engaging with people;
- Learn from people's experience;
- Translate lessons into practice;
- Keep up the momentum.

It helps to agree dates and times of meetings well in advance, so that people can make a commitment to attend.

IN KIRKBY

It took some time for the project group to gel. At first it was very dominated by professionals. However we soon learned to respect the contributions of the older people and eventually the professional status did not seem to be important.

Some professionals (myself included) had to learn the hard way that older people do not automatically follow the same rules and conventions as ourselves. For

example, we never knew how many people would attend a meeting – sometimes we expected two and ten turned up, sometimes vice versa. Because of their passionate interest in the subject, the older people on the group would often discuss matters which were not strictly on the agenda. However, this was a two-way learning process and we eventually reached a mutually comfortable way of working together.

We met in the council chamber of the local authority. Although this was not strictly 'neutral', it was sufficiently separate from any one service organisation. It was also a comfortable room and geographically well situated.

We learned to arrange meetings at times convenient to all, which generally meant meeting towards the middle of the day. We found that arranging lunches was a good incentive for people to attend.

We agreed a plan of action along the lines suggested here. Initially our plans were over-ambitious, but we learned to make them more realistic as time went on.

4. Agree an approach to engaging with people

The aim of the exercise is to find out about and learn from the life experiences of older people in order to develop more effective services and supports for them. The approach suggested here differs from that often used. Instead of using questionnaires or interviews, put more emphasis on getting to know the person and spending time with them. You will gain a much richer picture of their life and the elements that are important to them.

We suggest that each member of your group (working either alone or in pairs) spends some time with an older person in their own home. More than one visit is suggested. The first can be an introduction, where you explain the basis of the work and arrange to call again.

There is no set agenda or questionnaire. The purpose of the visits is to get to know the person and allow them to get to know you. Instead of conducting an interview, try having a conversation. If the person doesn't speak or doesn't say very much, simply spend time with them.

There are three general areas to explore:

1. What is life like for the person you are visiting?
2. What support do they receive?
3. What do they think of the support they do (or do not) receive?

It is surprising how much you can learn this way.

The stages involved are:

- identify the person;
- get an introduction from a relevant professional;
- check whether the person is prepared to be visited at home;
- go and meet him or her at home to introduce yourself and explain why you are there;
- spend time with the person over the course of one or two further visits;
- after each visit, make notes of the main issues which arose.

Engaging with groups of older people

Another way of collecting information is to meet established groups of older people, for example church groups, luncheon clubs, and groups at day centres. This allows you to reach more people, but does not give the same in-depth information as individual meetings.

IN KIRKBY

Members of our project group worked in pairs. One of the pair was an older person and the other was a professional. We agreed that the older person would take the lead in the meetings and the professional would be responsible for making notes afterwards.

We arranged a preparation day for the project group. This included:

- briefing the group about the purpose of the exercise;
- reviewing the overall approach;
- discussing how to collect information (asking open-ended questions);
- discussing confidentiality – we agreed that information obtained about individuals should be confidential to the group;
- agreeing who will visit whom, and when;
- setting up review groups to look at the information collected (see 5, below).

We agreed to contact individuals and groups. The plan was that fifteen individuals or couples would be visited at home, and six groups would be visited at the resource centre, a church group, a pensioners' group and a luncheon club. In practice, for various reasons we met fewer individuals and groups (see 6, below).

5. Identify people to engage with and arrange visits

You will need to identify people to visit. You may be able to work with a list of people already known to health and social services, or there may be other ways of identifying suitable interviewees (for example those known to various community groups).

You may wish to meet a wide range of people, those who need a great deal of support as well as people who need little or no help.

Next, you will need to approach people and ask if they are willing to take part. Think about the best way of arranging a meeting. It is not acceptable for a stranger to visit an older person at home without some form of introduction. The professionals on your group should be able to arrange for people to be approached and asked if they are willing to participate. You may have to arrange identification for those making the visits.

IN KIRKBY

We decided to visit people who were already known to health and social services. We approached people of retirement age or over (although we recognised that it could be useful to visit people approaching retirement age to get their views). We drew up a list of all older people living at home and divided it into three groups – people who were seen as 'heavy' users of services; those who were 'medium' users and people who were classified as 'light' users. We picked our sample equally from each group, to ensure that each classification was represented.

We met some 60 people. Eight were visited at home by pairs of project team members. The rest were met in groups at the resource centre, a church group, a pensioners' group and a luncheon club.

Although we had planned to meet more individuals, some people backed out and some of our project group also dropped out at the last minute (through illness and for other reasons).

6. Learn from people's experience

Spending time with people, individuals or groups, will produce a wealth of information – about people's lives. It is important to make brief notes after each visit or meeting, noting down the important issues that arose.

You must then assemble the information so that more general lessons can be learned based on the experience of individuals. One way of doing this, which we tried in Kirkby, was to hold *review meetings*.

At the review meeting pairs of information collectors meet a facilitator (who is also a member of the group) and each pair reports on the individual or group they visited. The facilitator then helps the group to reflect on the issues arising from the visits:

- what is this telling us about people's lives?
- what is their experience of services (and lack of them)?
- what needs to change to improve people's lives and experience of services?

A meeting of the entire project group is arranged, at which each review group makes a report. The project group then identifies the overall messages obtained from the work. These may subsequently become presentations to key individuals and contribute to a written report of the exercise.

The diagram on page 8 illustrates how the entire process works.

IN KIRKBY

We tried to set up six different review meetings. In practice this didn't work out. People sometimes needed to attend more than one meeting (some people made more than one visit) and it generally proved difficult to

organise a series of meetings. Eventually we arranged one day where all members of the project team would attend and spend time in review groups. This seemed to work well.

We also found that asking people to report back as if they were the individual they had visited ('My name is Jane Smith. I live alone at 3 The Broadway. I find it difficult to get out' ... etc.) was very effective in giving a vivid picture of that person's life.

The entire project team then spent a couple of hours reviewing the information and putting it on large sheets of paper on the wall. By the end of this process we had drawn out a wealth of information about older people, their experience of life and of services, and had agreed some important areas for action.

7. Translate lessons into practice

This is the difficult part! It is relatively easy to collect information about people's lives and services; it is often much less easy to ensure that action takes place to address problems.

You can start by preparing a presentation to senior people in, for example, health and social services about the project and what it found.

Having senior representatives from service organisations on your group may help. If they have been involved in meeting people and hearing about their lives, they may well share a general enthusiasm for getting things done.

Draw up an action list, include all the important issues identified and specify what needs to happen to ensure that change takes place. It is important to allocate responsibilities and dates to each action item. People can then take action individually or in small groups. This means working with a range of people and organisations outside the project working group. It may be important for the entire group to meet from time to time to ensure that the action stays on track.

HELP IN THE HOME

Collecting information



Visiting people at home



Meetings

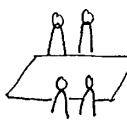


Other information

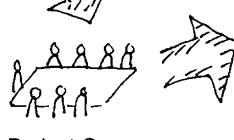
Making sense of the information



Review meetings



Presentations



Project Groups



Telling Health Social Services etc.

8. Keep up the momentum

IN KIRKBY

We arranged a presentation to the director of social services and the deputy director of commissioning of the health authority. We presented a few of the real-life stories of people we met, and were told that this made for a very effective presentation.

We agreed a list of eighteen action areas and allocated responsibility to members of the project group for tackling these. We also produced a short report of the work, to be circulated to all participants and to key people in service organisations (see Appendix 2). This included a list of the areas where we planned to take action. Some of these areas were part of work which was already being undertaken (for example improving discharge arrangements from hospital). Members of the project group made contact with individuals and organisations, including the housing department, the police, and the local Member of Parliament, as well as others within health and social services.

The project group arranged a series of meetings over a further six-month period to follow up on the action list and ensure that the work continued.

If this work proves useful, it will be good to ensure that the process of *engaging* with older people continues. The process is intensive and time consuming and there is unlikely to be the energy to repeat it at regular intervals. However by this stage you may have formed a committed group of older people and professionals with a unique experience of working productively together. You may wish to continue to harness this energy, for example by forming a different sort of planning team, with real involvement from older people and a commitment to improving services. Some of the action areas may be major ones, and there will be opportunities for people to continue to work together on them.

IN KIRKBY

We agreed that the process was useful, although there was little enthusiasm for repeating the information collection exercise. (We had originally planned to carry out a second round of visits, including meeting some people who were not known to health and social services.)

However, the group did agree that useful working relationships had been established. The working group

met on a number of occasions and took action on most of the issues identified.

Since we stopped collecting information a number of developments have taken place in Kirkby which have built on the work of the project. These centre on three initiatives:

An Older Person's Strategy Group has been established to inform the development of social services for older people in the borough and the links required with health and other agencies. This group held a series of workshops with older people, carers, professionals and managers and its draft policy reflects the issues identified by the Kirkby group.

The local authority and the health authority have established a Knowsley Health Plan Steering Group. This aims to develop a comprehensive strategic plan for improving the health of residents and those working in the borough. Much of the work on the health plan will be undertaken by focus groups examining a range of issues (income, poverty and health; communities, families and health, crime and health; access to health and social services; etc.). The active involvement of local people is being sought and many of those involved in our work will be asked to participate.

A local advocacy service for older people has been set up on a small scale pilot basis. This involves many of the people from our project and gives free advice to pensioners. It will also provide a valuable means of keeping in touch with a wide range of older people in the community. The service operates for two hours per week for an initial six-month period, but may be extended with additional funding.

The project has had an impact on the way people think about services for older people and has resulted in changes. It may be too early to gauge the full impact of the work, but there are positive indications that it is influencing the way services for older people in Kirkby are planned and run. Some members of the original group have left for new jobs or for other reasons.

Reflections on the Kirkby experience

What can we learn more generally about the approach used and about older people and the services they may need?

The approach adopted in Kirkby

The approach in Kirkby involved starting from scratch by making contact with older people. We tapped into existing networks, but did not identify a single 'user group' to work with from the outset. This is because there was no one group which represented older people in the area to speak on their behalf. There were various local user-groups, for example luncheon clubs and church groups, but none of these set out to be representative. The nearest to such a group was the Kirkby Retired Members Association, several members of which played a leading part in our work. We therefore took a conscious decision to start with a small number of enthusiasts and to build from there.

It is useful to distinguish between groups of service users who speak for themselves and those organisations which speak on behalf of particular users. There are a number of groups which powerfully represent older people. However, it is less common to find groups of older people with a voice of their own. This situation contrasts with other groups of people who use community care services and who are often well represented by established self-advocacy organisations. Many areas have established carers' groups, for example, and in some places groups already exist for people with learning disabilities, physically disabled people, people with mental health problems, etc. With older people, the starting point may be the pensioners' movement, or other local organisations which already represent them. It is important to involve one or more groups of older people, not just groups which speak for them. It could also involve other organisations, such as those which actively involve older people as volunteers in befriending or good neighbour schemes.

Our experience also suggested that the relationship between groups of older people and service organisations may change as terms of engagement develop. For example in Kirkby there had in the

past been friction between some local councillors and the Retired Members Association. During the course of this work, the older people on our group were able to play a different, constructive role working with service organisations, rather than solely lobbying against them.

There is probably no quick and easy way to set up working relationships with older people. There is probably no one person or organisation which can slip into the required role. Much effort will be needed to follow up local contacts and slowly build a working group.

Community living and services

The exercise in Kirkby was designed to understand older people's life experiences rather than trying to establish levels of satisfaction with particular services. We took this decision deliberately because we wanted more than a simple satisfaction measure. We believed that health and social services should ultimately have a beneficial effect on the quality of life, and it was this aspect we wanted to focus on.

This approach looks more broadly at the impact of services on people's lives and does not necessarily give the detailed critiques of services which are sometimes required. However it does give health and social services the chance to assess their impact in a more general way and may help decide longer-term priorities for change and for collaboration within and between different agencies.

What did we learn about life for older people in Kirkby?

The project taught us useful lessons about the perceptions of older people and about their lives and the services they receive. We learned that most people liked living in Kirkby, although many were not well off and said that general amenities, such as shops and transport, were unsatisfactory. People spoke positively about 'Kirkby folk', although many we met led isolated and lonely lives. There was a feeling that older people were generally not valued and, with notable exceptions, not really cared about by the community.

There was little direct criticism of health and social services. People generally seemed to have low

expectations and were reluctant to complain. Many spoke very positively about their home care workers and the resource centres they attended. There was a general acceptance that social services, in particular, had few resources and people seemed reluctant to ask for additional help. Some people said that they were prepared to contribute towards the cost of services (such as adaptations) to speed things up, but this was not allowed. There were mixed comments about GPs, who were judged on the amount of time they spent listening to people. Where people were visited by community nurses or therapists, these were well received.

There were tales of bad experiences people had received from council and health services and from public utilities. These related to poor 'customer care' (poor telephone manner, lack of information, long delays, etc.). There were some specific criticisms about discharge arrangements from one hospital.

Although we did not meet people who received no services, we heard complaints about the way services are rationed and the problems caused by providing help only to those in the greatest immediate need. People were also unclear about what services were available and how to gain access to them.

We also heard comments about the 'social fabric' in Kirkby. People were concerned about the dilapidated state of parts of the area, worried about young people on the streets and fearful of the drugs culture. Others expressed fear of crime and the fact that the streets and parks were felt to be unsafe.

There were concerns, too, about state benefits. A number of people were uncertain about their entitlement. Others were reluctant to apply for additional services in case this adversely affected the benefits they were receiving.

Where people did indicate that they wanted additional services, these were often in areas which have been affected by cutbacks and targeting (heavy housework, gardening, someone to 'pop in'). However for some people these would have a beneficial impact on their quality of life.

We also came across situations in which informal carers (often older people themselves) were taking on huge care tasks with a minimum of support from statutory services.

The overall picture was of older people surviving, often in fairly deprived conditions, but leading lonely, isolated and bored lives. Generally, services were helpful, but expectations were low and people were reluctant to ask for more or complain.

What did we learn about the approach in Kirkby?

We developed an approach which focused on *engaging with* older people in two ways. First, we engaged with a group of active and articulate people who joined the project group. We then went on to engage with older people living at home, meeting them individually and in groups.

We learned important lessons about ways of engaging with older people on the project group. It was not enough to invite two 'token' older people onto the group. We only made progress when we used existing networks to recruit a range of people and took time and effort to meet them on their own terms.

We took a deliberate decision to set up a joint working group that included both older people and professionals. An alternative would have been to establish a group containing just older people. We felt that it was important in the long term to ensure that professionals and older people were both fully involved, thus building in *engagement* from the start. We wanted professionals to develop their experience of meeting and working with older people.

The lessons we learned about mixing professionals with older people in a joint working group are as follows:

- use existing networks to find people who might be interested in joining a working group;
- spend time with people on their own territory, explaining the project and the reasons for wanting to work with them;
- try to explain the work in plain English, avoiding jargon wherever possible;

- recognise that older people will have their own views. Try to accommodate these within the working group;
- try to recruit sufficient numbers of older people so that they are not a minority. Ideally, try to have a group with equal numbers of older people and professionals;
- if you want people to attend meetings, think carefully about when they are held (convenience), and where (accessibility, 'neutral' venue). Some people may require assistance with transport. We found it helpful to meet around lunchtime and to provide lunch;
- consider arranging small group meetings so that people can be briefed and are able to think about issues before attending a larger group meeting;
- ensure that people who participate in meetings are taken seriously and treated with respect. For those who do not have experience of 'official' meetings, these can appear very daunting and it takes time for people to develop the confidence to participate;
- accept that people will not always stick to the 'rules', for example, turning up when expected, keeping to an agenda, talking one at a time, avoiding 'awkward' questions;
- allow leadership to develop among older people.

We also learned important lessons about engaging with people in their own homes or in discussion groups:

- try to arrange for visits to be made by two members of the project group, one of whom is an older person ;
- behave as an individual and try to leave any professional affiliations behind;
- ask open-ended questions, so that people have scope to say what they want (see 'Notes for Information Collectors', Appendix 3).

Strengths and limitations of this type of approach

The approach used in Kirkby had a number of strengths:

- older people from the community were actively engaged and formed constructive working relationships with professionals;

- the project gave a broad picture of life in the community for a wide range of older people who used health and social services;
- we identified a wide range of issues affecting the lives of older people receiving help in the home;
- the project itself generated a great deal of commitment for change from all who took part.

The limitations were:

- the project required concentrated effort and commitment on the part of a number of people – older people, those working in services and an external consultant. This level of commitment may not be readily available everywhere;
- the project did not look at those older people in the community who did not receive services. We did not gather information about those who may have slipped through the net of health and social services provision;
- the project provided a snapshot of the lives of a relatively small number of people. Although the issues raised were relevant to the support of people at home, it did not set out to provide numerical information about the relative size of problems identified. This would require further work.

Views of older people involved in the work

The older people who took part reported a number of positive views and some disappointments. They were pleased with the way that the group in Kirkby was established and with their role in it. They felt that a constructive working partnership was established between themselves and officers in health and social services. They also felt that the group went over the same ground a number of times and did not always progress as fast as it might have. The visits to older people at home provided useful insights and highlighted many issues of concern. They were pleased with the action list which emerged and the progress made on it. They also found the work enjoyable.

Their main disappointment was that the engagement appears to have ended with the conclusion of the project, particularly with the lack of participation in the Older Person's Strategy Group. They felt that a good constructive working

relationship had been established which could have contributed to the development of strategies and services. In addition there was concern that the advocacy initiative established was limited and short term. Nevertheless they saw this as a useful opportunity for the future.

From project to mainstream – keeping this sort of initiative going

The work in Kirkby took a great deal of effort to set up and sustain. The King's Fund provided a consultant to lead the project, together with a small amount of money, matched by the health authority, to support the involvement of older people. The local administration was more time-consuming than we initially expected, especially the logistics of organising visits and matching the people to carry them out. Many of the older people on the group had a range of other commitments, such as working with Victim Support and running the Retired Members Association, as well as their family commitments. The professionals too, of course, had busy lives.

One important feature of the work in Kirkby was the mutually *constructive* nature of the engagement. Some of the older people on the project group had had very negative relationships in the past with both officials and local members. Both sides learned to listen to the other and treat what was said with respect. The older people felt that they were taken seriously and their views were central to the work. Officers from both health and the local authority were similarly treated with respect by the older people.

There was not a great deal of enthusiasm for the planned second round of visits, and these were dropped. However, there was much commitment from the project group to ensure that lessons were learned from the work and action taken on the areas identified. They continued to meet for several months to work on these areas and have reported good progress.

At the time of writing no steps have been taken to continue active engagement between older people and officers in health and social services. The Older Person's Strategy Group does not include regular

membership from representatives of older people, which suggests that the Kirkby project was a one-off information collection exercise. However, it is possible that the group will establish continuing arrangements to engage with older people: the potential certainly remains in Kirkby to continue the process.

The work may also continue through the plan to set up an information centre and advocacy group for older people in Kirkby. Several older people on the working group are involved in this initiative and, if their efforts succeed, this will continue to 'tap' the experience of older people and ensure that their views form an integral part of the way services are planned and reviewed. At present the venture is short term and part time, but there are hopes that it can be developed.

Lessons for the longer-term maintenance of this sort of initiative seem to be:

- ensure an outside stimulus for a concerted effort to establish ways of engaging with older people;
- do not expect a separate concerted effort to be sustained for more than a few months;
- however, such an effort may change expectations and working practices by older people and those who work in or plan services, so that more collaborative relationships are established;
- this may depend on a *constructive* working relationship being set up. If the engagement with older people follows a pattern of attack and defence, it is unlikely that this will be sustained;
- find ways to continue this constructive engagement by ensuring that people who have had a positive experience of working together have further opportunities to do so during the course of long-term planning and review arrangements.

Implications for services for older people

There are a number of lessons from Kirkby which may be relevant to services elsewhere:

- Community care services cannot be seen in isolation from other aspects of people's lives. Health and social services are part of a wider set of influences such as leisure and shopping

facilities, transport, housing, crime prevention, churches. Any agency drawing up a strategy for the development of services for older people living at home would do well to work collaboratively with these other organisations.

- The active involvement of senior managers from both health and social services was crucial to the success of the project and provided a channel for them to talk to older people and listen to their views. There may be occasions when older people are reluctant to speak frankly in the presence of senior managers and we must ensure they can speak in confidence if they so wish. However, services generally could benefit by setting up mechanisms by which senior managers actively engage with those who receive services. While 'user participation' in planning and working groups no doubt have their benefits, this project demonstrated the advantages of an entirely different form of joint working on much more equal terms.
- Better ways must be found to get information about services and benefits to those who need it. Leaflets and directories by themselves may not be the best method of doing this. Much depends on word of mouth and information is passed through informal networks. With older people, there are existing channels which could be better used for disseminating this information and providing personal contacts – day resource centres, church groups, luncheon clubs, pensioners groups, etc. What may be needed is written information supported by regular personal contact from someone who knows about services and benefits. This contact will need to move beyond those who attend clubs, centres, etc. and build on the extended networks of older people in the community.
- Customer care is essential. Services should ensure that enquiries are dealt with politely and promptly and that information is given in ways which are easy to understand.
- Flexibility of service will enable older people to remain supported in the community. Where services are based on 'packages' of care, it is important that these are more than a few standard options (five hours of home care, three days in a resource centre, four hours of district nurse, etc.), based on good individual

assessments. If more thought is given to the exact nature of the services which support individuals and their carers, people will be better assisted to remain in the community and enjoy a reasonable quality of life.

- Flexible individual packages of care may need to include options which are not generally provided (heavy housework, gardening, monitoring visits or phone calls). Evidence in Kirkby suggested that introduction of these would have a beneficial impact on the lives of some people.

Leadership among older people

The work in Kirkby was a good example of how leadership among older people can be nurtured and developed by statutory services. Before the project started there were already active groups of older people in the area and we were able to tap into the energy and commitment of some of these groups and encourage them to work constructively with professionals.

The success of the work was highly dependent upon the leadership shown by some of the older people who participated. One local organisation in particular played an active role in voicing the opinions and concerns of a wide range of local people. A small number of individuals within that organisation were crucial in enlisting and sustaining support for the project.

Lessons for the centre

What are the lessons from this project which are relevant to central government? The work tested one particular approach to 'citizen participation' and also illustrated the impact of current policies at a local level.

- The project demonstrated one way of successfully engaging with older people around the development of community services. The model piloted in Kirkby and outlined in this report could be one way in which services nationally might move beyond 'user involvement' towards engagement. This could have implications for the way that people are engaged nationally (for example in groups which work directly with central government) and for

the guidance which is issued to local and health authorities about the ways in which they work with users of services.

- The issues raised above under 'Implications for services for older people' are likely to have a relevance nationally, and central government could play a leading role in ensuring that services respond to the issues raised here.
- The Kirkby experience suggests that policies regarding older people (especially those regarded as 'vulnerable') may need to be reconsidered. This will mean developing healthy communities where older people can expect a better quality of life (an improved physical environment, safer neighbourhoods, accessible transport, leisure opportunities, etc.). Such changes will require connections with wider public health and urban regeneration agendas.
- The work also has implications for the way we think and act about quality in public services. Perhaps we should focus on broader quality-of-life issues as well as the direct impact of service delivery. Broad assessments of the effect of policies and services could incorporate some of the working methods reported here.
- Central government is charged with setting new policy priorities and directions. It may be helpful to take fresh approaches to engaging older people's interest. A new vision will require re-engagement on the lines suggested by this project. The Department of Health and the NHS Executive could adopt new ways of working with older people and play a useful role in sponsoring information exchange on innovation and good practice in involving older people in service development.

APPENDIX I: USEFUL READING

This is not a comprehensive review of the literature, but briefly summarises some of the work which informed the approach we took in Kirkby.

Age Concern (1996). *User Involvement in Age Concern – A reader*. Available from Age Concern England, Astral House, 1268 London Road, London SW16 4 ER. This booklet contains a range of contributions reflecting different approaches to user involvement. It discusses different levels of involvement and examines broad strategies for involving older people and goes on to give a variety of examples of involvement in local projects.

Marian Barnes and Gaynor Bennett-Emslie (1997). *If They Would Listen ... An evaluation of the Fife User Panels*. Available from Age Concern Scotland, 113 Rose Street, Edinburgh EH2 3DT. The Fife User Panels were established to enable frail older people to discuss with each other their experiences of growing older and of using health and social care services. The discussions were used to influence services to be more sensitive to older people's needs. This report describes the panel model, evaluates the work, discusses the issues which emerged and the response of the statutory agencies.

Jocelyn Cornwell (1989). *The Consumers' View: Elderly people and community health services*. London: King's Fund. This report draws on a wide range of published work and discusses what elderly people and those who care for them want from community health services. It includes guidelines for working with older people and tailoring services to meet their requirements.

Sheila Fletcher (1995). *Evaluating Community Care: A guide to evaluations led by disabled people*. London: King's Fund. The Living Options Partnership supported two projects where disabled people carried out evaluations of community care services in their area. This report draws on the experience of these projects and suggests ways of setting up, and using, a user-led evaluation.

Melanie Henwood (Editor) (1998). *Our Turn Next: A fresh look at home support services for older people*. Jointly published by the Joint Initiatives for Community Care, the King's Fund Development Centre and the Nuffield Institute for Health. In autumn 1997 an expert seminar was held in London bringing together health and social care purchasers and providers, voluntary sector organisations and older people. The report of the seminar discusses current experiences and suggests radical action to achieve a new vision in home support.

Mike Oliver and Bamber Postance (1996). *Service User Involvement in the Development of Home Care and Agency Services*. Available from Bamber Postance, University of Greenwich, School of Social Sciences, Avery Hill Road, Eltham SE9 2HB. This reports work for the Joint Commissioning Agency for Greenwich Health and Social Services looking at consumers' views about the development of community care services. Disabled or older people were interviewed and invited to take part in focus groups. The project generated a wide range of views about existing services and a consumers' quality agenda for domiciliary services.

Patricia Thornton and Rosemary Tozer (1995). *Having a Say in Change: Older people and community care*. York: Joseph Rowntree Foundation. This report looks at different ways of involving older users of community care in having a say about the services which affect their lives. Three initiatives were studied in detail: a service users' action forum, a postal network, and a telephone discussion group. In addition the project was supported by an Older People's Advisory Group. Contains useful advice on the practicalities of involving older people.

Rosemary Watts (1997). *Report of the 'Have your Say' Project. Independent Advocacy Service, March 1997*. Obtainable from Independent Advocacy Service, 131 Camberwell Road, London SE5 0HF. The aim of Have Your Say is to involve older people who have difficulty getting out and about in having a say about their community care services. The report discusses a six-month pilot project which involved a postal network, a telephone discussion group and a newsletter. The report summarises the views of the people consulted and sets out some options for future work.

Gail Wilson (Editor) (1995). *Community Care: Asking the Users*. London: Chapman & Hall. This book contains a number of contributions from researchers and others describing different approaches to finding the views of people who use services. Of particular interest to me was a chapter by Gail Wilson entitled 'Low expectations reinforced: experiences of health services in advanced old age'. This describes how interviews with older people about their experiences of life uncovered a range of problems and complaints about health services which they would probably have been reluctant to mention if asked directly.

APPENDIX 2: HELP IN THE HOME

Working with older people to improve community services

What we found in Kirkby

Help in the Home involved older people in Kirkby working with health, social services and other organisations. We wanted to find out what older people who live at home think about their lives and the help they get.

We went out to meet some older people, either in their own homes or in groups such as luncheon clubs, church groups or resource centres. All together we met about 60 older people.

We would like to say thank you to all the people who met us, and also to the people who went out and listened.

What people told us

About life in Kirkby

- Most people told us that they like living in Kirkby – especially the friendliness and support they get from the local community.
- However, many people also had worries – about crime, drugs and vandalism and were frightened of some young people.
- There are people who do not go out much and are lonely, isolated and bored with life.
- Transport can be difficult, especially for those who have problems with mobility.
- It was felt that shopping facilities in Kirkby are poor, especially if you can't easily get into the town centre.
- Many people do not have much money. They can't afford holidays, for example.
- There are those who were persuaded to buy their council houses but now can't afford to repair them.
- Someone told us 'Once you are older, no-one really cares about you or how you live'.

About the help they get to stay at home

- People were usually very positive about the services they get in the home (home care, district nurses, etc.). We were told that home care workers were good, but that the service was expensive. Sometimes people don't turn up when they say they will, or if a worker changes job, no-one else comes instead. Some people had appliances which needed repairing.
- There were people who wanted additional help, such as with heavy housework and gardening, or someone to run errands for them or take them to the shops. And there were those who wanted someone to 'pop in' and keep an eye on them.
- People were generally positive about sheltered accommodation and the resource centres for older people. They were concerned that only people in sheltered accommodation can get reduced-rate TV licences.
- Some people thought their doctor took time to listen to them. Others felt that their doctor was pressed for time and didn't listen.
- Some people had been sent home from hospital at weekends without any food in the house or anyone to look after them.
- Several people complained about the housing department, saying that they were sometimes rude, didn't do what they said they would do, and took a long time to finish even simple repairs.
- Many people didn't expect much from social services, because they thought that there was not enough money to provide help. Several people said that they didn't expect much help: 'I try to do as much as possible for myself so as not to be a burden'.
- People were reluctant to ask for help in case this meant that they would lose benefits. People didn't know what benefits they were entitled to. Someone told us: 'It all depends who you know – people who know the system never go short'.

- Generally, people wanted a more positive and flexible approach to enquiries.
- Some people told us that they were prepared to contribute towards the cost of services or adaptations, but that this wasn't allowed. 'It's all or nothing'.
- People didn't know what help they were entitled to. They didn't know how to obtain information. Many people found it difficult to get to central places such as the Town Hall.
- People thought that the services provided by churches were only for people who attend that church.
- There are people who are looked after at home by an elderly relative who receives little or no support.
- We were told of the problems someone had in trying to get British Gas to repair their cooker quickly and cheaply. They were without a cooker for several days.

Action

So far we have had a meeting with the director of social services and the deputy director of commissioning of the health authority. They are keen to do what they can to improve life for older people living at home.

- We have drawn up a list of things to be done over the next six months and are getting on with them
- We have set up a group of older people and professionals to make sure that things get done
- We are telling everyone who took part in the project about our findings
- We are making a list of all the facilities and activities for older people in Kirkby
- We are supporting a new advocacy service for older people in Kirkby
- We are seeking ways to develop links between older people and younger people through local schools

- We will be contacting the police, the housing department, the leisure department, Age Concern and Mersey Travel to tell them about the anxieties we heard
- We will be working with the carers development officer to ensure that carers of older people get good support
- The health trust is making sure that every person over 75 years of age is offered a health check-up every year
- The health authority and the trust are making sure that proper arrangements are made when people are discharged from hospital
- We are writing to the local MP and the TV Licensing Authority to see if it is possible for older people to get reduced rates on their TV licences
- We are looking at ways in which people might be able to get the extra help they need (gardening, heavy housework, etc.)
- Social services are investigating more flexible ways of financing equipment and adaptations and are speaking to the people who provide equipment
- We will be telling local churches that people think they have to be members to get help from them
- We will be contacting British Gas about the way they handle enquiries about repairs
- We will be talking to the housing department about their customer care and the attitude of staff
- We are contacting local shopkeepers to see how to improve shopping facilities
- Social services and health are looking, with older people, at what information is available about services and how people can get this information

We hope to have made progress on all these items within the next six months.

APPENDIX 3: HELP IN THE HOME PROJECT

Notes for information collectors

This is just a reminder of some of the things we have already discussed.

Arranging visits

We will be visiting in pairs. In most cases the professional in the pair will arrange the visit. If necessary, get an introduction from the link worker.

First visit

The first visit to people in their own homes is just an introduction.

- introduce yourselves and the project
- let the person get to know you
- arrange a second visit – and agree roughly how long this will be (about an hour)
- explain about confidentiality

For those visiting groups, you can probably ask for people's views on the first visit. There may be no need for a second visit.

Second visit

This is the main opportunity to get people's views. The service worker in your pair will act as note taker. Your colleague will be the interviewer. Remind the person you are visiting that what they tell you will remain confidential.

Note taker

- Remember to let the other person do the talking and ask the questions. You are just there to take notes
- Take notes discreetly – don't put people off

Interviewer

Your job is to help the person talk about their experience and views

- let the person you are visiting do the talking
- remember what we discussed about open-ended interviewing
- the green sheet contains topics that might be useful in the interviews

Review groups

After your second visit, you will meet other information collectors to discuss what you have found. The person facilitating your review group will be in touch to make arrangements.

Project group meeting

There will be a project group meeting on 13 January to discuss the findings of the project and how we use the information that we have collected. Everyone involved in collecting information is welcome to attend.

Confidentiality

We have all agreed to the following:

We will not discuss anyone we have visited by name (or so they can be identified) outside our pair or review group. It is important that we don't 'gossip' about the people we visit.

Emergency situations

In the unlikely event that you come across an emergency situation (someone is very upset, very ill, being abused, etc.):

- do not try to solve the problem
- if the person wants help and gives permission, contact the appropriate professional
- make notes of what happened

Open-ended interviewing – tips

- Use a lot of open questions, such as 'What happened?', 'What was it like?', 'Tell me more about ...', 'What do you think of ...?'
- Listen and follow on from what the person has said
- Gently guide the conversation back if going completely off the subject
- Don't give your own opinions too much
- Give as much encouragement as you can
- Summarise and check back

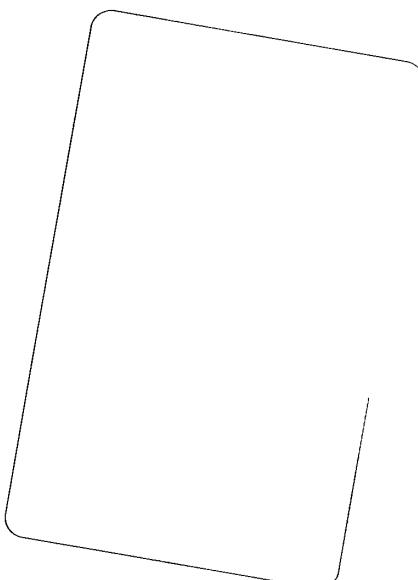
Good luck!

Acknowledgements

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WHO IS THIS WRITTEN FOR?

Terms of Engagement will be of interest to a wide range of people, including:

- Groups of older people – who want to ensure that their voice is heard, particularly those who are campaigning or negotiating for improved services. Just such a group was closely involved in the work which led to this paper
- Senior managers in health and social services – with responsibility for providing services, who have a genuine interest in making sure that the support people get is in line with what *they say they want* and who are working to develop services which are both responsive and cost-effective
- Councillors and other community representatives – who want to ensure that older people get good quality support to help them stay at home
- Officials in health and local authorities and in the Department of Health – with responsibilities for developing policies, who share an interest in ensuring good quality support in line with the views of older people
- Researchers and others – who are interested in the views of older people and different ways of finding out about people's experience
- Anyone who is concerned about living in old age – and who feels, like me, that *I want to be sure that the right sort of supports is there if and when I need them*

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