PREVENTING DEPENDENCY AND PROMOTING INDEPENDENCE OF OLDER PEOPLE

Key issues for improving performance in health and social care



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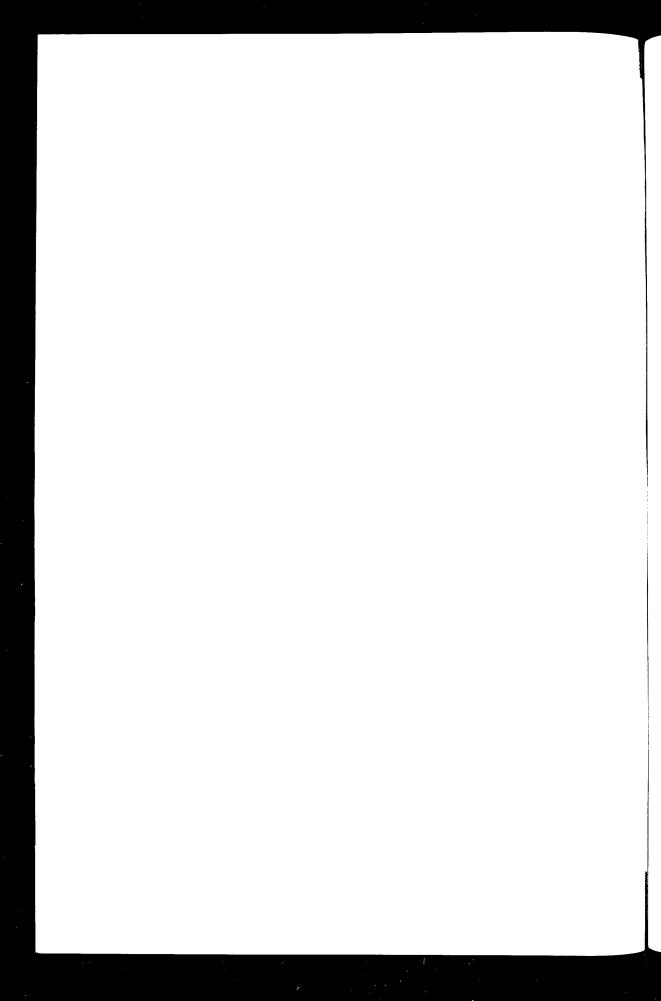
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Key messages from King's Fund review

This briefing paper has been produced by the King's Fund for the NHS Executive London Regional Office and the London Social Care Region to inform the design and delivery of a new Older People's Service Development Programme in London. The ultimate goal of this programme is to promote the independence of older people in London through the development of person-centred coordinated services. In order to achieve that goal the aim will be to establish systems to identify vulnerable older people in the community who may be at risk of increasing dependency on services, and to ensure that this is informed by the voices of older people and their carers.

This paper reviews the evidence regarding effective preventive approaches and describes innovative developments taking place. It focuses particularly on the systems and processes that are needed to ensure that older people who are at risk of increasing dependency are identified, assessed, and then have access to well-coordinated treatment, care and support that will enable them to lead independent lives.

The King's Fund review indicates that staff, users and carers involved in the London service development initiative will:

(1) Be working in an environment where there are substantial barriers to be overcome in order to achieve improvements in the care system. There is little shared understanding about preventive practices that promote independence; there has been weak implementation of preventive policies to date; and many staff (especially those in primary care) report low morale and intense work pressures.

Implications for development

It will be important to:

- find ways of engaging key stakeholders in service improvement initiatives;
- develop the knowledge and skills of key players very quickly;
- focus on the 'do-able', achieving early successes;
- make connections with performance targets that have already been set and that act as motivators for senior managers in health and social care.
- (2) Be able to build on current UK innovative practice, where collaboration between health and social care agencies has been a key feature. The evidence suggests that such collaboration is needed to identify older people at risk, and to follow through with assessment and care management that ensures continuity of care and support. It also warns of the dangers of single agencies trying to 'go it alone' by, for instance, adopting narrowly conceived health screening, or by PCTs engaging their own care managers.

Implications for development

Service improvements will require:

- building and sustaining a network of agencies and staff who have a role to play in promoting the independence of older people;
- paying attention to points in the care system where older people are at risk of 'falling through the net' and where there are opportunities to spot difficulties and intervene early.
- (3) Need to develop better ways of involving older people and their carers in screening, assessment and care management. Older people value preventive approaches that enable them to stay in their own home and exercise choice and control over their lives. However, there is scope for improvement right across the spectrum of involvement, ranging from individuals making decisions about their own health and care, to participation in service planning

Implications for development

It will be important to consider:

- the role older people and carers should play in designing and overseeing service improvement initiatives;
- the types of information required by older people and carers at every stage of any service improvement initiative;
- training required to enable front line professionals to adopt a more person-centred approach.
- (4) Have to choose between different preventive approaches to suit different purposes. Choices have to be made between universal and selective screening, and between intensive and more general care management. In making those decisions due regard will have to be given to prevention priorities, the merits of targeting particular at risk groups, and considerations of equity and cost-effectiveness.

Implications for development

Starting from such a low base, it will be important to:

- identify the scale of service improvement that will be most feasible in current circumstances, choosing between across the board improvements affecting all older people, or more limited and focused initiatives;
- target preventive efforts where there is confidence that effective interventions can be offered to people once they have been identified as 'at risk' and able to benefit;
- determine how success might be measured, recognising the dangers of only 'measuring the measurable'.
- (5) Have access to only limited evidence about effective practice. Evidence about preventive approaches is generally under developed and patchy. It is stronger in the realm of preventive interventions, such as falls, stroke, etc, than in preventive processes, such as case finding, assessment and care management. Cost effectiveness data is scarce

although stronger on intensive work with high service users than it is on health promotion with people showing few signs of ill-health or other difficulties.

Implications for development

- There is no blue print available showing 'what works' when promoting the independence of older people.
- There are some important pointers for success which can be used to compare current and future performance.
- Improvements can be made by building on what is known about effective practice, but testing out new ways of working will also be required.
- (6) Have to build staff capacity to adopt a whole systems approach. Communication and persuasion/negotiation skills will be at a premium for building and sustaining the networks needed to operate effective case-finding and case coordination. Sophisticated systems for gathering, collating and using information about individuals' health and well being will also be necessary.

Implications for development

It will be important to

- train staff in using basic techniques such as at risk registers, care pathways, and protocols, etc;
- speed up the development of electronic information systems that aggregate and share information between staff/across boundaries;
- develop information-sharing and liaison procedures that smooth the path of users and carers through the service system.
- (7) Need to consider the availability and suitability of existing preventive services and design improvement strategies accordingly. The evidence suggests that processes designed to improve the access of older people to preventive interventions are only as good as the capacity of the service system to meet previously unidentified needs. Hard pressed staff, struggling to meet current demands, are likely to be cautious and possibly resistant to new ways of working. Users themselves may refuse interventions offered if they are unacceptable/unsuitable. Questions about responsibilities for service development arise in job descriptions for care managers, in the remit of multi-disciplinary teams and in divisions between strategic and operational management.

Implications for development

It will be important to:

- recognise that systems of case-finding, assessment and case coordination cannot be divorced from interventions offering treatment, care and support;
- anticipate the capacity of the service system to respond to new cases identified;
- plan service responses that will assist older people identified at risk of increasing dependency.

1. INTRODUCTION

This briefing paper has been produced by the King's Fund for the NHS Executive London Regional Office and the London Social Care Region to inform the design of a new Older People's Service Development Programme in London. This new programme aims to develop better integrated, community based services which allow older people to live healthy, fulfilled lives. The ultimate goal is to promote the independence of older people in London, through the development of person-centred coordinated services. In order to achieve that goal, the aim will be to establish systems to identify, and to deliver a single assessment to vulnerable older people in the community who may be at risk of increasing dependency on services, and to ensure that this is informed by the voices of older people and their carers. In this respect, the programme is intended to facilitate the implementation of the National Service Framework for Older People⁽¹⁾ in the capital.

This paper focuses broadly on preventive approaches that can be adopted to maximise the independence of older people. When discussing 'preventive approaches', we make a distinction between therapeutic interventions, (including medical treatment, therapies, health promotion activities and social support) and systems and processes (such as screening, assessment and care planning) that facilitate access to and coordination of those preventive interventions. We concentrate on the latter, recognising that much of the criticism of services for older people is centred on failures to identify people in need before they are in crisis, and to work with them in planning and coordinating a combination of health, social care, housing and other support required.

These failures are, no doubt, why the National Service Framework for Older People places great emphasis on improving person-centred care, setting standards for a single assessment and integrated commissioning and provision of services. Without improvements in these basic processes, there can be no prospect of meeting other NSF standards requiring action to prevent strokes, falls and mental health problems.

We recognise, nevertheless, that such interventions cannot be entirely separated from the way the care system works. The real or assumed availability and acceptability of care services will affect the extent to which staff proactively seek out people at risk of increasing dependency and make arrangements for them to receive particular kinds of support.

The paper concentrates on ways of working where there is widespread agreement that there is scope for improvement. We consider what is known about

- ways of identifying people who may be at risk of becoming dependent
- systems that need to be in place to trigger and carry out a single assessment wherever older people enter the health and social system
- ways of developing coordinated packages or pathways that promote independence
- systems required to gather and act on the views of older people.

Drawing on evidence about effective ways of working, we explore key issues, pose questions and point out the implications that particular issues have for service improvement strategies. We also provide some examples of innovative practice that illustrate how some staff are trying out new ways of working.

2. PROGRAMME ENVIRONMENT

The proposed service development programme on older people's services will operate in an environment where

- · 'prevention' has different meanings;
- where policies stressing prevention and health improvement have had only a limited impact in practice;
- where the evidence regarding the effectiveness of preventive approaches is limited.

We consider this environment in more detail, recognising that the success of the programme and its constituent projects will depend on shared knowledge and understanding of preventive approaches and on the existence of incentives and other influences motivating people to work in new ways.

The concept of prevention

Older people and the management of demand

In discussions about 'prevention', it is not always clear what is being prevented and why. Stress is continually being placed upon preventing avoidable admissions of older people to hospitals and care homes. (2) The motives here are related to reducing service use by older people, so that waiting lists can come down and the 'vicious circle of expenditure' on institutional care can be broken. There is, at the same time, a concern to prevent or delay avoidable deterioration in the health and well-being of older people, maximising the extent to which they are able to retain their independence.

These two objectives can be presented as different sides of the same coin, where it is recognised that many older people would not need to go into hospitals or care homes if there was earlier intervention to prevent crises occurring and if there were alternative services providing appropriate care and support in their own homes. It is worth noting though that there can be tensions when preventive approaches are interpreted as being primarily in the interests of the Government or service providers rather than older people themselves. This has been apparent in some of the discussions about intermediate care as a way of reducing 'bed-blocking'. (3)

Definitions in health and social care

Prevention can also conjure up different meanings among health and social care staff. In the health service, concepts of primary, secondary and tertiary prevention prevail. Thus primary prevention is about preventing or delaying the onset of disease and other health problems, through health promotion strategies (eg, reducing smoking, levels of obesity, etc, in individuals, building stronger social networks or improving the physical environment). Secondary prevention is about screening populations and individuals to identify and treat health problems at an early stage, thereby preventing further decline or deterioration. And tertiary prevention refers to the process of managing existing disease to limit its impact on life or to slow down the rate of deterioration (eg, through equipment and adaptations, packages of care that maintain people living at home, continence promotion in care homes). (4) In the health service, these distinctions may be more familiar to public health departments and to geriatricians than they are in general practice.

In social care, prevention is often equated with practical assistance in the home, such as low intensity home care, gardening, home repairs and maintenance, and with day care that prevents carer breakdown. ^(5,6) This overlaps with low intensity housing support, such as wardens and housing support workers, equipment and adaptations, etc. It is seen as early intervention for people with relatively low levels of need and, as such, an alternative to the common practice of crisis intervention.

However, there are signs of greater convergence in the way health and social care staff think and talk about prevention. For instance, the Association of Directors of Social Services (ADSS) applies the concepts of primary, secondary and tertiary prevention when discussing strategies that social services departments should adopt to promote the quality of life of older people and to reduce the need for residential and nursing home care. Whether this understanding is shared among operational, front line staff is not known.

Prevention as health improvement

Prevention is an objective in health improvement strategies, where there is a continuum of activities aimed at individuals, groups and communities. These include:

- specific treatments, therapies or social support provided for individuals by health and/or social care agencies, eg GPs prescribing aspirin for people with coronary heart disease;
- educational materials and sessions enabling particular groups of people to learn about their health, action they can take to prevent difficulties arising and ways in which they can manage their own care. NHS and social services have a role to play here, but so do voluntary organisations and self-help groups, educational bodies and the mass media;
- building healthy communities, by tackling poverty, improving housing and transport, creating safe neighbourhoods and building social networks. Responsibility lies with many different agencies, with health and social care playing their part in collaboration with others.

Prevention policies

Providing care or promoting independence?

Prevention and the promotion of health and well-being have been clear policy themes throughout the last decade. However, those policies have been weakly implemented, as health and social care agencies have struggled to respond to people with acute and severe needs for care and support. Moreover, the focus on older people in those policies has until recently tended to be weaker than that on children and younger adults.

Thus, in health policy, successive governments have aimed to prevent illness and disability - as well as treating people when they are ill or injured. This is evident in the Health of the Nation 1992, ⁽⁸⁾ Our Healthier Nation 1998, ⁽⁹⁾ A Modern NHS 1999⁽¹⁰⁾ and the NHS Plan 2000. ⁽¹¹⁾ The emphasis of those policies changed quite dramatically in the late 1990s, with a Labour Government attaching greater importance to economic and environmental approaches to health improvement and to reducing health inequalities among disadvantaged communities, while the earlier Conservative Government had focused more on the adoption of healthy life styles.

The focus on older people in prevention policies has been evident in Age Well programmes, safe neighbourhood initiatives, and the recent commitment to develop more intermediate care. National Service Frameworks aimed at tackling the killer diseases of cancer and heart disease, and the suicide rate associated with mental illness have also focused on prevention - as has the NSF for Older People, which set standards for the primary and secondary prevention of stroke, falls and mental illness.

While successive governments have developed policies designed to prevent or reduce illness and disability, these have always been of secondary political and professional importance when compared to the priorities of treating and caring for the sick. Consequently, prevention and health improvement policies have been only weakly implemented.

In social care policy, Caring for People 1990⁽¹²⁾ which preceded the community care reforms, aimed to promote independence and to prevent avoidable admissions to hospitals and care homes. This policy has not been realised as social services departments have had to target over-stretched resources on people deemed to be in greatest need of (long term) care. More recently, there have been attempts to encourage more preventive services, through a Prevention Grant⁽¹³⁾ but the sums of money made available have been small compared with that allocated for general social care services.

Measures of success

There are now joint policies and priorities requiring health and social services to work together to promote the independence of older people and to prevent/reduce emergency hospital admissions and rates of admissions to care homes. (14) The incentives for agencies to improve performance have been strengthened by a performance assessment framework that judges and rewards agencies that are seen to be making good progress. Whether these

incentives are strong enough to motivate the health and social care workforce to improve the way they work remains to be seen. Many report low morale, high work pressures, and an irritation with the number of central initiatives, with GPs especially exhibiting signs of 'feeling battered'. This may serve to weaken the implementation of joint policies.

Nature of the evidence

There is only limited evidence about the effectiveness of preventive approaches in health and social care. Furthermore, much of the research undertaken to assess the impact of preventive approaches has not involved people over the age of 65. Evaluation of preventive approaches in health and social care can be very complex, particularly where social, as opposed to bio-medical, interventions are concerned and it can take many years before the impact (in terms of sustained health and well-being) can be properly assessed.

Having said that, the evidence relating to preventive interventions is stronger than that relating to preventive processes. For instance, there is strong evidence⁽¹⁵⁾ that the following are effective in preventing or minimising ill health and reducing the use of health and social services:

- vaccination for influenza
- stroke rehabilitation
- falls prevention, involving a combination of personal and environmental interventions
- education for the self management of chronic conditions, like arthritis (where improved health outcomes include a reduction in pain and in depression)

The evidence about effective strategies to prevent the onset or reduce the impact of mental illness in older people (depression, psychosis or dementia) is mixed.

There is a smaller body of research about effective practice in case-finding, assessment and care management. The strongest evidence relates to comprehensive geriatric assessment, (16) which - when followed by care planning - is known to improve health and well-being and to reduce the use of institutional care. However, the research does not indicate what are the most effective ways of carrying out those assessments. For a more detailed understanding of best practice in assessment and care management, practitioners have relied upon a mixture of Department of Health and professional guidance (17) and feedback from users and carers. (18)

IMPLICATIONS FOR DEVELOPMENT

The history of prevention and health improvement policies means that most staff at all levels will not be accustomed to preventive ways of working nor of promoting independence rather than dealing with dependence. It is likely that senior managers will be interested in preventive approaches that will help them to meet targets, and receive a 'clean bill of health' from central government. However, 'early adopters' may feel, at times, that they are working against the tide as they try to engage all the relevant stakeholders in service improvement initiatives.

With so many definitions and interpretations, there is considerable scope for confusion and conflict when staff, users and carers consider what might be done to improve preventive ways of working. It will help if those engaged in service improvement strategies have a shared understanding of the different purposes and types of preventive action that can be taken.

The limitations of current evidence means that there is no blue-print showing the best way to improve older people's access to relevant sources of help nor the coordination of the different types of help offered. There are some pointers for success, but there is a great deal of scope for testing out new ways of working and for making professional judgements about the best courses of action.

ISSUES FOR THE ADVISORY PANEL

- What needs to be done to engage key stakeholders in service improvement initiatives?
- How can the knowledge, skills and understanding of project participants be developed to maximise the chances of success?
- What connections can be made with performance targets that have already been set and that act as 'motivators' for senior managers in health and social care?

3. THE INVOLVEMENT OF OLDER PEOPLE AND THEIR CARERS

Any effort to prevent deterioration in health and well-being and to promote independence will require the active involvement of older people and their carers (where they exist).

The value older people place on prevention and independence

Older people tend to equate 'independence' with an ability to stay living in their own home and with exercising choice and control over their day to day lives. They value interventions that prevent them losing that independence. Many appreciate low levels of help in the home that make it possible for them to remain there, maintaining their own self respect and social contacts. Health promotion activity is also valued by patients (young and old) when they consult their GP, especially among those who are frequent attenders at GP surgeries and who are worried about their health. When consulted about their priorities for health in old age, older people rank highly services that prevent or delay decline and that facilitate recovery from illness or injury. It cannot be assumed though that all older people in all circumstances will prefer and accept these sorts of services their views need to be explored on a one to one level. This is why such significance has been placed on person-centred care in the National Service Framework.

Older people's experiences

Health and social care agencies frequently declare their aim to involve older people and carers in service planning and in their own care. However, in practice, the extent to which patients, users and the wider public are involved falls short of what is required. (22,23) These shortfalls are particularly evident in the way service staff currently identify people at risk of increasing dependency, assess their needs and coordinate the care and support considered necessary to promote independence.

Older people and carers can experience difficulties in:

• Communications: The use of professional jargon is known to be a problem eg, What is case-finding? What is an assessment? Some technical terms may be interpreted differently by professionals and public eg, an 'at risk register' may sound innocent enough to primary care professionals but may be threatening to some members of the public who associate such things with child abuse. Time and again users and carers have expressed dissatisfaction with the amount and type of information they are given by health and social care professionals. This applies to information about their own health and care plan, but also about their entitlements, options and any risks they may face as a consequence of particular interventions. Poor communications are most evident when practitioners fail to treat older people as equals, neglecting to explain why they are being approached for screening, what happens in an assessment etc, and what the consequences of particular decisions might be.

- Relationships with professionals: The most common complaint is that older people are not treated with respect, are not given opportunities to have their say and are seen as passive recipients of care. (24) Carers too complain that they are 'ignored and invisible'. (25) Paternalistic attitudes (however benevolent) among health and social care practitioners have to be overcome if there is to be any prospect of older people participating fully in decisions affecting their own health and well-being.
- Coordination and continuity of care and support: Older people and carers frequently express frustration at the number of people involved in assessing their needs and planning their care. They dislike having to provide the same information over and over again to different people. They are also often unsure who is in charge of their 'case' and who they should contact when things go wrong or circumstances change.
- Response to cultural and ethnic diversity: Failings to recognise the specific requirements of older people in black and ethnic minority communities have been evident in inadequate consultation processes and in the way information is shared and disseminated.

Examples of good practice

There are many encouraging developments aimed at improving user and public involvement. Examples include :

- the development of videos, audio cassettes and written materials providing information about health issues and service options, and enabling individuals to make informed choices about their own care. (26)
- the development of shared decision-making approaches in the education and training of health professionals (particularly doctors). (27)
- the growth in patient participation groups, user focus groups and local forums involving older people and carers. (28)
- early attempts at person-centred approaches to assessment and care planning. Some of the most impressive efforts involve work with young adults who have learning disabilities, but good practice with older people is also evident in some of the newly created rehabilitation or re-enablement teams. (29)
- Copies of patient records and care plans held by individuals in their own homes.
- User-led schemes, where older people have used direct payments to buy the help they need (eg, in Portsmouth)⁽³⁰⁾; have set up self help health promotion programmes (eg, in Bromley); and have taken control of their own care by participating in self management of care programmes (such as those run by Arthritis Care).⁽³¹⁾

IMPLICATIONS FOR DEVELOPMENT

The reality is that there is scope for improvement across the spectrum of involvement, ranging from individuals making decisions about their own health and care to participation in service planning. Substantial improvements are needed in the way in which older people from black and ethnic minority communities are informed, consulted and involved in service planning. Changes are required in the practice of many different categories of staff working in the NHS, local authorities and voluntary organisations. Many health and social care staff are trying to improve the way they work with older people and there is much to be learned from their experience.

ISSUES FOR THE ADVISORY PANEL

- What role should older people and carers, including those from black and ethnic minority communities, play in designing and managing any service improvement initiatives?
- What kinds of information-giving need to be built into the different elements or stages of service improvement initiatives?
- How can individuals be supported to manage their own care packages, using direct payments?
- What scope is there for developing the training of frontline professionals to enable them to adopt a more user-centred approach?
- How can staff assess whether they are making progress in involving older people and carers, including those from black and ethnic minority communities?

4. IDENTIFYING OLDER PEOPLE AT RISK OF DEPENDENCY

(A) CASE FINDING

Definitions

Case finding is actively seeking out people who are at risk. It is based on the assumption that this approach will identify people who may otherwise not come to the attention of services at all or have some important needs which have been neglected. Approaches to case finding will be influenced by the cases (people) that you want to find. In defining levels of risk it may be helpful to consider four categories of people:

A	В	С	D
People who are	People whose well-	People who have	People who have
well but may	being has declined	developed	serious problems
accumulate	and are at risk of	problems but can	but can be helped
avoidable risk	experiencing	be helped to	to avoid getting
factors because	chronic problems	reverse the decline	worse
they are not aware	or crises.	in well-being.	
of the risks.		_	

Examples of risk categories in relation to diabetes and falls:

Diabetes			
Unaware of the link between eating and exercise habits and obesity, unaware of	ì	Has type 2 diabetes but no complications	Diabetes with neuropathy and other damage to circulatory system
risks of obesity			

Falls				
Unaware of link	Reduced mobility	Osteoporosis and	Several fractures,	
between activity	and poor lighting in	has fallen 3 times	frightened of	
levels, mobility and	home	but no fractures	falling, rarely	
bone density			leaves home	

People in any of the above four categories could be unknown to services that could provide them with help. For example, research suggests that people with type 2 diabetes have had the condition for between 9 and 12 years prior to diagnosis, and approximately one third have complications at diagnosis.⁽³²⁾

Whose responsibility is case finding?

In the case of diabetes it might seem that the GP is responsible for providing advice and detecting the development of problems. However, if the individual sees a chiropodist, attends hospital for a skin problem or is in a residential care home but has no contact with a GP, should the other services be looking for indicators of risk? Case finding systems need to be clear about who has responsibility within the system. This will determine the design of information systems, training and development.

Where to look for cases?

If existing systems for referral are not identifying all those at risk, how are these people 'falling through the net'? There will be two main ways in which this occurs:

- (1) People are not in contact with any services that might have responsibility for identifying risks;
- (2) People are in contact with some services, but the systems for identifying risk and assessing need are not as effective as they could be.

Approaches to case finding

Different approaches have been developed to case finding. Often they aim to target people in certain categories (see A–D above). How and where people are sought is also linked to what is known about the inadequacies of existing systems.

Universal screening of target groups

The target group is usually all people over a certain age that a particular organisation has information about or contact with. In the UK GP lists are most often used. In the US the members of managed health care schemes are targeted. Screening is undertaken at regular intervals. It is easiest to locate people where a list of this type with identifying characteristics (eg, age and address) exists. Targeting groups, such as people over 65 from minority ethnic groups, requires a reliable way to contact individuals.

Selective approaches

These assume that there are certain indicators of risk that are more likely to be missed when people come into contact with services. The approach is to increase the sensitivity of services in identifying people at risk. For example, bereavement is a known risk factor for depression. but there is no one source for finding people who have been recently bereaved. Annual universal screening, as described above, would be less effective in picking this up because of the time lag involved.

Examples of case finding

Universal screening and selective searches to identify high users in United States

The first systems in the US developed when it became clear that a small percentage of older people were using a large proportion (measured by spend) of services. Motivation was as much about reducing expenditure as about improving well-being. The aim is to identify people with chronic health problems at high risk of hospitalisation. Information is gathered in two main ways:

- Issue of a self completion questionnaire annually to all people over a certain age.
- Analysis of service utilisation data, which is routinely collected.

The information gathered is analysed for indicators of risk. If certain questions are responded to positively or the level of current usage exceeds a set threshold, a more detailed assessment will take place. Following this some people will receive intensive case management for a period of time with the aim of reducing future need for services.

There is evidence that hospital admission rates and lengths of stay have reduced as a result and that use of other services has reduced. (33)

Screening people before they become high users in the United States

In the US work is underway on screening processes to identify people affected by what they describe as 'geriatric syndromes' for which there are evidence based interventions. The syndromes they have focussed on are:

- Low physical activity levels
- Falls
- Depression
- Incontinence
- High risk medication
- Under-nutrition
- Dementia

Use of screening tools in UK

The requirement for GP practices to offer over 75s assessments has meant that a variety of approaches have been taken, some more formalised than others. Because implementation is patchy, coverage is far from universal within and between localities. There is no single tool used for this process in the UK.

Research into the value of over-75s assessments has been dogged by controversy about the validity of studies and the implications of findings. These assessments do identify health and social needs that were not previously known about or met. The controversy is about

how significant these needs are, the costs of assessment compared to the outcomes and whether studies were rigorous enough. (34) (35) (36)

A more systematic approach has been used in Hammersmith and Fulham (Keep Well at Home project) where all patients aged over 75 years on GP lists receive a copy of a standardised questionnaire and responses are classified as to whether they reach a threshold indicating a more detailed assessment or follow up is needed. Non-responders are followed up systematically. Evidence from the service suggests that previously unidentified need has been found and that interventions have reduced risk of deterioration. (37)

Identifying significant patterns of service use in the UK

In the UK information on service utilisation is not coordinated into one record, in some cases it is not recorded at all in a way that links the individual to service use. Various approaches are being taken to pick up this information and feed it into a service that can judge whether further assessment might be needed. Some of these are set out below.

- In Runcorn one GP practice uses a computerised record system that is said to record all episodes of NHS care (presumably not social care) per patient. This is used to identify high users of services, who are then followed up. No published data is available on outcomes. The staff involved indicate that hospital re-admissions, A&E visits and GP consultations for the target group of patients have reduced.
- Systems to identify people who fall are being developed in some areas (eg, West Surrey) by ensuring that ambulance services record all cases where they provide help to someone who has fallen whether or not they are taken to A&E. This information would be sent to a service able to assess risk and organise further assessment if needed.
- Other systems rely on building up a network of services that are alert to certain indicators of risk. For example people with chronic health problems who do not appear to be in contact with services that might provide assessment and help. The EPICS model is one that has been developed in the UK. (38) Indicators might include repeat attendances at A&E, levels of contact with primary health care team, calls to council help-line, changes noticed by home care staff, or problems noticed by wardens in sheltered accommodation.
- In some areas work is underway to set up 'at risk' registers based on information from key services. People on the register would be assessed and plans made both for immediate support, if needed, as well as the potential for future intervention.

Using screening to target health promotion interventions

The approaches described above are used to identify people who fall in categories B-D (as shown on page 15). The work developing in the US on 'geriatric syndromes' would pick up some people at stage A.

Case finding and assessment

When people at risk have been found they require assessment before decisions can be made about the type of support that is appropriate. This implies a distinction between case finding/screening and assessment. In reality some assessment is taking place at the point of first contact. Looking at the responses to a brief postal questionnaire or considering whether a change in mood is unusual, is an early form of assessment. Case finding is one way of increasing the likelihood that a fuller assessment will be triggered for people at risk.

(B) TRIGGERS FOR ASSESSMENT

The success of case finding rests on:

- Knowing what information will best enable you to distinguish people at risk from those
 who are not at risk, ie knowing the social, psychological, physical and environmental
 factors which are predictive of adverse outcomes. The information you seek will
 depend on which category(ies) of people (for example A-D above) you are interested in
 finding.
- Having a reliable way to gather the information.

Actual and potential users can come into contact with services via various routes. Case finding is a way of spreading the net as wide as possible. Effective systems for identifying and responding to risk have to combine four elements:

(1) People who recognise risk

People can find out about risk factors through experience, training and information as well as the availability of standardised screening tools.

(2) People in locations where they are likely to identify risk

People who spend time in contact with the target group providing information, advice and support.

(3) People whose roles enable them to actively seek information

There are a range of people working in different settings who are in a position to actively seek out further information and to follow through or refer on for some further action. GPs, receptionists, district nurses, residential care staff, pharmacists, etc, are obvious examples of people who have clear opportunities to spot difficulties when, for example, older people request repeat prescriptions, have their medication changed, are vaccinated against 'flu, fail to attend appointments, or whose carers are ill. Other signs might indicate the need to seek further information, such as apparent anxiety about going out alone, signs of trouble with eyesight, or increased alcohol consumption. Housing wardens,

home care workers, volunteer drivers, or day care staff are in a position to spot these signs if they see that as part of their role.

(4) People who know what to do when they identify risk.

Systems are needed to ensure that information can be acted on and further assessment organised where needed. Protocols and a network of contacts are needed.

Case Finding/Assessment and Service Provision

Case finding and assessment is designed to take some people along a pathway leading to services or advice on self-help. The types of information gathered is influenced by the services available. This is one of the reasons put forward for having very open ended assessment where pre-defined domains are not assumed. For example, relying on an assessment tool that measures Activities of Daily Living (ADLs) will only provide information about an individual's functional capacity, eg ability to climb stairs unaided. Such tools do not identify wider aspects of independent living. (39)

Some objections to case finding are based on the belief that services will not be available to meet all the needs identified. This concern may relate to different beliefs:

- That the volume of services are insufficient and therefore it is not ethical to assess people who have no hope of getting services.
- That there are no evidence-based interventions for some problems so it is pointless seeking them out.
- That if people choose not to present themselves to services it is unethical to 'invade their privacy' by probing for information or worry them by asking questions about their well-being.

These objections have been challenged on the grounds that

- It would be unfair to ignore people who are not in the service system but who happen to have the same level of need to those who are. Refusal to case find only allows inequality of access to continue.
- While there may be no effective medical treatments for, say, Alzheimer's Disease, there are psychological and social interventions that can improve the quality of life for people with those conditions and their carers.
- There need be no ethical problem as long as individuals are informed about the process and give their consent.

Involvement of Users and Carers

At the earliest stage of case finding it is possible to involve users and carers. If someone in contact with an individual suspects that there may be a problem, discussion with the person is both ethical and likely to help clarify the situation. The response to postal questionnaires has to be voluntary and any follow up with the consent of the individual. There are choices to be made about how fully and genuinely people are enabled to express their views and preferences at all stages.

Being effectively involved means having access to information about the process, the assumptions being made by assessors and the scope of any outcomes.

IMPLICATIONS FOR DEVELOPMENT

There are a number of choices to be made when developing better systems to identify people at risk of increasing dependency. There is no one right way to undertake effective case finding. It will help therefore if people engaged in case finding are clear about:

- who they are trying to find and why;
- who is responsible for identifying people at risk, and for following through with assessment and care planning;
- what support will be made available once people's needs have been identified.

ISSUES FOR THE ADVISORY PANEL

- Which types of screening should be given priority in the new development programme?
- What will help people in the field decide about organisations to be included in any case finding systems?
- Given the current requirement to undertake over-75s assessments, how should these be considered within the development of case finding and assessment?
- What will help people in the field overcome some of the likely objections to case finding?
- How can organisations increase the awareness of individuals about their own health so that people are more likely to identify risks to their own health and act to reduce them?
- How can case-finding assist the initiation of the single assessment process?

5. CASE COORDINATION

Introduction

Coordinating care packages in response to the assessed needs of older people and their carers is a core part of delivering person-centred care (Standard 2 National Service Framework for Older People). Good, comprehensive assessment and care planning, which properly engages with the older person and their carer, and involves them in decisions about their care, is crucial in ensuring the most appropriate services are provided. Coordinating these processes and services, so there is no unnecessary duplication and good continuity of care, promotes older people's independence by preventing deterioration in their health and home situation and by managing crises. At best, it should ensure older people use services and support in a way which gives them control to live where and how they prefer.

There have been many different approaches to case coordination, particularly within the field of social care. These include examples of service users managing their own package of services. The different models provide pointers for success and highlight the tensions which health and social services will need to address in considering the most effective arrangements for the future.

Different approaches to 'case coordination': Case and care management

The processes of case and care management have been defined and re-defined over more than ten years. Although there may not be a universally accepted definition of case and care management, there is some consensus that the main components are screening, assessment, care planning, implementation, monitoring and re-assessment. (40)

Commentators distinguish between a model of 'intensive care management' where care managers coordinate services for people with long term, severe and complex needs and a more general definition of the process of care management. The latter refers to organisational procedures in place to ensure discrete tasks of assessment, individual care planning and regular reviews are carried out for all service users. This differentiation is important given the evidence that even with very careful targeting of case management services there is little overall saving in costs, although improvements in welfare. Case management with its overhead costs of the case manager, will, for those with less severe needs, tend to be cost raising. (41)

A survey of care arrangements in all English local authorities in 1997 showed little evidence of intensive care management in older people's services and a lack of involvement of healthcare staff in care management. (42)

Models of case management

Different models of care management have been classified (43) as:

- (a) single worker/single agency model, where there is a one-to-one relationship between client and care manager;
- (b) shared core tasks model, where tasks are undertaken by different staff;
- (c) independent agency model, akin to service brokerage for particular clients or groups, which can enhance client advocacy by distancing case managers from resource considerations but may weaken the case manager's leverage within service systems;
- (d) joint agency, where case management is supported by a multi-disciplinary, cross-agency team. A number of problems have been identified in grafting case management on to multi-disciplinary teams, as interpretation of the case manager or key worker role may be coloured by the professional background of individual workers, so clients experience a different service according to who they see. It is also difficult for key workers to monitor long term cases as well as provide a short term service to other clients of the team.

Evaluation of different models of case and care management indicate the importance of:

- defining the nature, structure and goals of care management (44)
- targeting care management on appropriate cases (45)
- developing appropriate legitimacy and mechanisms to give care managers influence in the services providing network
- devolved budgets to allow care managers to purchase care (with good financial monitoring systems)
- appropriate size of caseloads
- time to plan individual care programmes and establish rapport with client
- continuity of involvement of the same care manager with service user (46)
- attention to standards and quality (as defined by the user)

There is also evidence that successful care management systems cannot be a 'bolt-on' but need to be an integral part of a comprehensive service design in which cultural changes are effected at all levels of the organisation. Care management arrangements need to be backed by all the support systems, including service planning and commissioning, quality assurance, management supervision, training and comprehensive information systems. (47)

Specific skills and knowledge have been identified for case managers, including. (48)

- interpersonal skills to negotiate with others
- good team and collaborative working skills
- excellent communication skills with a wide range of people

- ability not to be confined by own professional role⁽⁴⁹⁾
- ability to listen and work with clients rather than make plans on their behalf
- close working knowledge of needs of client group and local service and community resources
- technical skills in assessment and knowing when more specialist input is needed
- experience of working across a range of agencies and understanding of their role

These same skills and knowledge apply equally to key workers who may come from any professional background.

Other approaches to ensuring continuity of care

The Audit Commission's recent review of rehabilitation services⁽⁵⁰⁾ identified four different approaches to ensure continuity of care when transfers take place between services and organisations:

- i. *transfer protocols:* The Audit Commission identified a lack of these and at best found a reliance on verbal discussions or other informal exchanges rather than explicit protocols for transferring care plans.
- ii. ongoing outreach services that link to earlier services.
- iii. 'in-reach' services, where, for example in Sheffield, the multi-disciplinary community rehabilitation teams have recruited community rehabilitation liaison nurses. These liaison nurses ensure timely assessment as well as transfer of patients requiring the services of the rehabilitation team. They work with ward-based teams to assess clients and facilitate transfer to the community; liaise with community and social services; ensure information and communication between all the players; and support patients, carers and their families.
- iv. *key worker*, for example in North Devon Re-enablement Team a key worker is a named member of the team for the client and carer. The key worker sets therapy goals with patient and carer, keeps the team informed, liaises with all services, plans discharge and measures outcomes of any intervention.

The limitations of case coordination

Whatever method of service coordination and however sensitive and well-informed the case management process, the outcomes depend on the availability of appropriate local services and flexible support options. 'Ultimately it (case management) is limited in what it can do by how good services are'. (51) 'Continuity of care depends on the availability of day and community based services to complete rehabilitation, and to monitor and review progress'. (52)

Some care management models have had a specific remit to develop new services in response to assessed needs and their success has also been limited by how far those providing or commissioning services respond to requests.⁽⁵³⁾ Whilst the literature often highlights this broader service development function for care management, beyond coordination of services for the individual, in practice this has 'lagged behind in the UK'. (54)

User and carer participation in case coordination

Direct Payments (which local authorities have been able to make to older people since Disabled Children Act 2000) offer older people the option of coordinating and managing their own packages of care. A pilot scheme in one social services department (Portsmouth) to give older people more choice and control over their support arrangements showed the minority of older people who chose the personal assistant option received a high quality service. The main barrier to taking up this option was a lack of social networks to find someone suitable. The pilot intended to support a change in care management towards promoting user empowerment. Signs of a culture shift were clearly visible but there were tensions between protecting users from risk and exploitation; and between meeting individual needs better versus ensuring equity in the use of rationed resources. (555)

Evaluation of the use of direct payments for disabled people indicate this is a cost-effective means of service delivery when compared with similar support costs from inhouse service provision and agency support. (56)

Although good practice promotes the full involvement of both user and carer in assessment and care planning, there is evidence that care plans are not always meaningful or routinely given to service users, ^(57,58) information is often inadequate ⁽⁵⁹⁾ and carers do not always know their needs have been assessed. ⁽⁶⁰⁾

Examples of new models of case management to integrate health and social care

The following selection of examples has not been drawn from evaluated studies but they are descriptions from conference presentations and newsletters.

• Rehabilitation - A Case Manager approach

In North Carolina a rehabilitation service provides an example of case management which focuses on outcomes and the coordination of services from start to finish. Case management starts from admission when, within 24-48 hours of transfer from A&E, an assessment is made and a care pathway planned to discharge. Patient goals are agreed and the case manager, of any discipline, is responsible for moving plans forward and overcoming obstacles to discharge. The case manager is not based on any ward and follows the patient back into the community. This is not just about discharge planning but about coordinating the programme from start to finish. It is claimed the main outcomes of

outcome-orientated rehabilitation are improved patient care, better use of resources and good interdisciplinary working. (61)

• Case Management in Primary Care (Castlefields Health Centre, Runcorn)

Care managers with a nursing background based in the general practice target specific groups of older people and case find, undertake needs assessment, identify problems, plan interventions, organise support and monitor and evaluate outcomes. Results to date indicate reduced admissions to hospital, reduced bed occupancy, closer working between health and social care and a more responsive service, closer working within the primary health care team, improved primary-secondary interface and easier access to services for patients and carers. (62)

• Case management for people with chronic obstructive pulmonary disease

The Tameside and Glossop Community Rehabilitation Team has developed a case management approach to support people diagnosed with chronic obstructive pulmonary disease. The team consists of a social worker, occupational therapists, physiotherapists, nurses and rehabilitation assistants, with access to speech, language and dietetics services. The team offers people with COPD who are beginning to show a pattern of multiple admissions to hospital a six week package of rehabilitation structured around functional care pathways, followed by a period of proactive case management. A key worker is responsible for developing a therapeutic relationship with the user.

The model includes a needs-led multi-disciplinary assessment which involves patient and carer; identification of an evidence-based respiration pathway, maintenance plan, exacerbation plan; an on-call system and protocol, pro-active contact and hospital in-reach. All documentation used by the team is held by the user as part of the philosophy of empowering people through inclusion, education and information. (63)

• Woking PCG / West Surrey

Integrated health and social care teams are working to improve assessment and care planning in two ways. Firstly, by using a 'process map' which guides staff through decision points in the system. There are about 30 steps to go through in complex cases, about 4 in simple cases. This leads people towards care coordinators, team leaders and others responsible for taking prompt action. Secondly, they are working towards GPs putting information about patients in an accessible form that can be used in summary at various points in the system. The development of electronic records will make the assessment and care planning process work better.

• Other examples from the field

There is anecdotal evidence about a range of different approaches to case coordination. For example, general practices have appointed nurses to act as case managers; and specialist nurses, such as those for people with Parkinson's Disease, are coordinating care for patients. There is some feedback that the role of coordinators within different intermediate care schemes is now restricted to six weeks only which seems to be in line with the definition within guidance on intermediate care.

In Hertfordshire, health and social care coordinators have been appointed to prevent inappropriate admissions at crisis points and to coordinate health and social care services. These coordinators are based in PCTs and take direct referrals, aiming to provide a flexible response, for up to 2 weeks only, to deal with crisis situations. They have access to a budget and refer people directly to different health and social services. To date, most of the coordinators are social workers or occupational therapists.

IMPLICATIONS FOR DEVELOPMENT

The test of successful case coordination will be seen in responses to the preferences and choices expressed by older people and carers during the assessment process. The approaches adopted will determine the extent to which older people's expectations are raised or dampened. Arrangements must be made for the intensive case management of that small group of older people who have complex needs and who will need a combination of support from a variety of services provided by the NHS, housing, social services and others. For the majority of older people, shared information and liaison systems are required to ensure smooth pathways through the different parts of the health and social care system. This will entail transferring information gleaned from assessments and from individuals' records and care plans, and identifying designated staff with responsibility for checking that action is being taken following referral.

ISSUES FOR THE ADVISORY PANEL

- How can older people be fully engaged in new models of care management? Will
 older people have any choice as to who coordinates their case and will they have
 access to advocates where necessary?
- What part will new models of case coordination play in identifying gaps in services and inadequate quality? What structures and procedures need to be in place to tackle service deficits identified?
- Should efforts to improve case coordination focus on intensive case management for the few or less intensive approaches for all?
- How can staff acting as case managers, care coordinators or key workers best be supported in this role and helped to think outside of their usual professional role?
- What steps should primary care trusts, general practices and social care teams take together to improve case coordination of older people in their area?

Key issues for the Advisory Panel

These issues have been raised in the course of this review. They need to be considered by everyone engaged in service development initiatives aimed at promoting the independence of older people.

(1) Engagement

- What needs to be done to engage key stakeholders in the service initiative?
- What connections can be made with performance targets that have already been set and that may act as motivators for senior managers in health and social care?

(2) User involvement

- How can the perspectives and interests of older people and carers be built into all stages of the service improvement initiative?
- How can staff assess whether they are making progress in involving older people and carers in the programme?

(3) Development priorities

- Which approaches to case-finding will be most desirable and feasible for service improvement projects operating in the London area?
- Are universal or targeted approaches to screening more or less likely to lead to early successes?
- Should priority be given to improving intensive case coordination for older people with complex needs, or to improving systems of information-sharing and liaison for the majority of older people? Or should efforts be made to improve both simultaneously?

(4) Staff capacity

- How can the knowledge, skills and understanding of programme participants be developed (quickly) to maximise the chances of success?
- What scope is there for developing the training of front-line professionals to enable them to adopt a person-centred approach to the care and support of older people?

(5) Systems

- How can improvements be made in the type and delivery of information required by older people at different stages of their journey through the care system?
- What staffing arrangements and information systems are needed to carry out effective case-finding and case coordination?
- What arrangements will need to be made to collect and analyse information about service performance, which will in turn show whether improvements are being made?

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