King's Fund

Community Care Debates

The NHS & long-term care

– time for a new deal?

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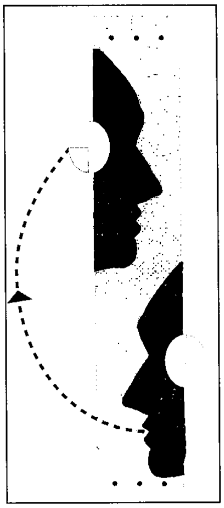

This question was posed at a debate organised by the King's Fund. The debate took place at a time when the NHS stood accused of withdrawing from long-term care, and public concern was running high about the growth of means-tested services previously provided free under the NHS.

People from different backgrounds agree that major problems have arisen in the way in which long-term care services are organised and financed. They also acknowledge that new arrangements will have to be made sooner or later. But, in the absence of a shared vision of what an acceptable new deal might look like, there is no agreement on action to be taken. There is, however, reluctance to return to a system fashioned in the 1940s, and an appreciation of the need to find new solutions – solutions which are as much about models of support required in a modern society as about methods of financing that support.

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Policy perspectives – *Alan Walker*

Consensus, conflict and crisis

The NHS has been withdrawing from long-term care for many years, relocating people who were living in long-stay hospitals into the community. The call for the closure of long-stay institutions was made by Enoch Powell in the 1950s and, for some 30 years, there was a consensus that community care was a good thing, enabling people with long-term illness or disability to live a normal life. Despite this consensus, the lion's share of health and social care resources was taken by hospitals and residential care establishments, and there were worries that community care was being viewed as a cheap option. However, there were no serious boundary disputes, like those we are witnessing now, over the respective responsibilities of the NHS and local authorities for long-term care.

The last 15 years

The consensus about long-term care began to break down in the 1980s, with a crisis looming in the 1990s. Conflict grew as the demand for long-term care increased, owing to demographic pressures and medical advances; as disabled people and carers voiced their concerns about services; and as ideological changes became apparent in policies.

Between 1981 and 1991, there was a 25 per cent reduction in hospital beds, as the earlier trickle of long-term bed closures became a flood. In contrast, the privatisation of long-term care in nursing homes and residential care homes proceeded at full throttle, stoking up expectations that were to be denied later in the 1990s.

Policies in the last 15 years have failed to address long-standing deficiencies in the organisation of long-term care. Underfunding has persisted, influenced by a 'flood-gate' mentality which fears that families might give up caring if the State provided better support for people with long-term care needs. A restricted conception of community care has prevailed, as has the predominance of service provider interests. In addition, discriminatory attitudes towards older people have been pervasive, as evident in the bias towards childcare in the personal social services and in the widespread assumption that residential services are acceptable for older people but not for the young. These long-term deficiencies, coupled with the recent introduction of a quasi-market in the NHS, have brought about the current crisis.

Growing need

Community care has become a nightmare. A care gap caused by growing need, coupled with tighter rationing and a focus on those in 'greatest need', means that many frail people are being denied any help at all. Local authority services are becoming residual ones. The perverse incentive to use residential care continues in the face of insufficient domiciliary care alternatives and the 85 per cent rule favouring independent sector providers. Relatives are forced to contribute to the costs of residential care, and it is estimated that between 30,000 and 40,000 people per year will have to sell their homes in order to meet the costs of care.

Government has changed the definition of long-term care, moving it away from 'health care' and into 'social care'. People with long-term illnesses and disabilities now undergo social care assessments which, unlike medical assessments, offer no guarantee of a service being provided when needs are identified.

A new vision

It is time for a new deal and a new vision. We need to make a fresh start, giving new status to long-term care and the Cinderella services associated with it. New options for resourcing long-term care will have to be considered. This is already happening. For instance, the Government favours private insurance, and it is expected that the Budget will include measures to encourage the conversion of private pension assets to pay for care, a change that will help less than 5 per cent of the people needing long-term care. If the US experience is anything to go by, many people needing care services (e.g. those with severe arthritis or rheumatism) would be excluded from taking out private insurance to pay for them.

The Labour Party favours a mixture of private and public insurance – a solution that tries to merge a German Bismarckian model with the British Beveridge model. This system would exclude people on low incomes, presenting a problem for women, who are the majority of people with long-term care needs. It also overlooks preferences among the British public for provision financed by taxation – a preference revealed in cross-national surveys.

My own vision for long-term care in the future is one that:

- recognises social care as preventing family breakdown and improving people's quality of life. This will mean investing in a substantial expansion of home care provision.
- erases discriminatory practice against older people and offers them opportunities for independent living.
- ensures that community care is governed by principles concerning rights of access and the rights of service users to take decisions concerning their own care. Community care has to be about empowering people.
- is resourced through general taxation in the same way as the care of people with acute illness is financed. This would spread the risk and provide solidarity between generations.
- reduces the organisational division between health and social care.

There may be a case for giving local authorities dual responsibility for health and social care, but such a reorganisation would be very disruptive. Joint commissioning authorities offer a way forward, reducing artificial boundaries and making more sense to users and carers. ❑

Family experiences and expectations

– Jill Pitkeathley

A new world of welfare?

The family is the prime provider of care. The ability of families to provide care is likely to diminish in the future as they become smaller; as mobility within families increases; as more women join the workforce; as 'serial monogamy' featuring increased rates of divorce and remarriage results in people having more relatives but weakened moral obligations to provide care; and as more disabled people demand independent living that does not rely on support from their relatives.

Disillusionment and disbelief

At the moment, there are no signs of these trends having an effect on the willingness of families to take on caring responsibilities. Nor is there any evidence of families expecting a great deal in the way of support – they always ask for so little. They do, however, expect help from the NHS, and many people are disillusioned and disbelieving when they find that there is no provision available or that they will be expected to pay for services which used to be free.

The image of a 'cradle to the grave' NHS is deeply embedded in the national psyche, and it is a cruel lesson when people find out what is actually happening in the health service. At the moment, most members of the public are not aware of the situation until the time comes when they or their relative need help. Calls to the Carers National Association indicate that when people find out, they do not like it. They say, 'I have paid my taxes', 'I've scrimped and saved all my life so that I can leave something for my children'.

The changes taking place in the NHS have happened by stealth. Social care has always been means-tested, but most of it was provided free by the NHS (mainly in geriatric wards). That is no longer the case, and we can therefore see a mismatch between beliefs about what is or will be provided and the reality.

Taboos

There is much resistance to discussing arrangements for long-term care. It is taboo in families, who do not like talking about the future when that means confronting death, disability and family relationships. Exhortations to plan ahead are often met with 'I don't want to think about it'. The media have not tended, until recently, to see this issue as a 'story', and politicians are reluctant to go beyond minor refinements in the current system and to take a root and branch, long-term view.

People are beginning to wake up to the problems now. Women journalists who might previously have focused on childcare are turning their attention to the long-term care of elderly infirm relatives. The press has also recently focused on legacies, noting the anger of old people who are facing having to sell their homes in order to pay for their care and, no doubt, relishing the embarrassment of politicians whose policies make them look foolish in the eyes of their electorate.

Facing the challenge

The problem cannot be solved by political expediency, trying to patch up the situation before the next election. We need a debate considering some fundamental questions about the family and the State, including:

- how can we find a fair balance of responsibility in caring between families, alternative forms of care and the State?
- how can policies and services promote independence?
- do children always have a duty to look after their parents?
- what is the family's duty to see that care is provided if they cannot do the actual caring themselves?
- should all family members have the same degree of choice as to whether to care?
- should children expect to inherit parents' resources or should those resources be used to pay for care?
- what should people who have 'paid in' be entitled to expect?
- how can we compensate people who give up work to care for someone else? Any future policy must have the rights of users and carers at its centre. It will also need to address considerations like setting age limits for carers (can they be 3 years old or 90 years old?); providing minimum packages of care offered as of right and guaranteeing carers time off from caring; and charging users or carers for services.

The debate must be in public and not left to politicians. Service users and their families must be involved. The issue should be addressed in manifestos being prepared for the next election. What is most important is that any new deal with the NHS must include a fair deal for caring families. ❑

Primary care realities – *Pat Gordon*

An alternative vision for managing long-term care?

The debate about the NHS and long-term care tends to focus on what hospitals do or don't do. I want to look at another part of the NHS, namely primary care, and the contribution those services make or could make to the support of people with chronic illness or disability. This is important at a time when there is a policy promoting a primary care-led NHS.

Responsive services

Primary care services, including general practice and community health provision, are well placed to help people with long-term care needs. They can be more acceptable and responsive to people with chronic illnesses, most of whom experience uncertainty, stigma, fears of treatment and associated side-effects, lack of control or mastery (either real or perceived) and emergent conditions which evolve and change over time, requiring frequent readjustments in management as well as treatment of acute episodes.

The nature and range of primary care services mean that, potentially at least, people can have the relative ease of access and frequency of contact necessary for managing changing patterns of illness and disability.

There is a huge range of services within the network of support that we call 'primary care'. Individuals can refer themselves directly to those primary care services and, if necessary, be referred into other care domains such as hospitals. The degree of specialism among professionals may change as people move from primary to secondary care services, but primary care professionals, who are generalists, possess considerable expertise.

A primary care-led NHS

The call for primary care to be the mainstay of the NHS is not just a fashion nor a cheap option. It is an acknowledgement that institutions institutionalise. It is a recognition that it is not therapeutic to live (or stay for long periods of time) in hospitals. As new solutions become possible, we can provide care in normal community settings rather than in hospitals or other institutions. While nobody wants wilting hospitals and blossoming surgeries, there is a strong case for providing help within primary care, as long as this can be done safely. But the desired strategic shift towards high-quality community-based health services is unlikely to succeed without a well-developed network of primary health care providers.

A unique system

Primary care offers distinctive benefits, with its two main providers possessing the capacity for managing long-term care in community settings:

- general practice
- community health services.

Looking first at general practice, it is clear that we have a unique system in the UK which is led by expert generalists (GPs), who practice biographical medicine (i.e. dealing with illness in daily life and providing continuity of care); provides universal coverage on a 24-hour basis; has referral rights to hospital; and operates on a teamwork basis (with generalists supported by other specialist practitioners), and in small organisations (which are accessible and non-institutional).

Community health services comprise networks linking professionals who may be generalist nurses or community-based specialists in paediatrics, diabetes care, etc. They provide models of home care and intensive nursing care. Their core business includes the care of chronically ill people and support for people discharged from hospital. Community health services offer people a choice, especially important when family-based care is not appropriate.

Primary care with its interwoven specialities and therapeutic connections adds up to a system of great strength and flexibility. Of course, it does not always work like this. Like community care and secondary care, there are great variations in general practice and in community health services. Nevertheless, we have the essential building blocks – although it is not clear whose responsibility it is to develop effective primary care providers. Instead, the policy interest in primary care at present is focused on its role in purchasing other services (especially secondary care).

Within the NHS, primary care services already make the major contribution to the support of people with long-term care needs. More could be done with an effective primary care development strategy which supported the work of generalists, both doctors and nurses; maintained a scale appropriate to personal care organisations; managed chronic illness as an emergent condition and not a series of events; and managed networks and boundaries as part of the core business. ❑

People from the following organisations attended this debate:

Age Concern Greater London; Allied Dunbar Charitable Trust; Alzheimer's Disease Society; Arthritis Care; Association of County Councils; Baring Foundation; Barnet Health Agency; Carers National Association; City Parochial Foundation; Counsel and Care for the Elderly; Department of Health; East Sussex District Health Authority; Gatsby Charitable Foundation; Greater London Association of Community Health Councils; Greater London Forum for the Elderly; Hillingdon Borough Council; Hillingdon Health Agency; Institute for Public Policy Research; Joseph Rowntree Foundation; King's Fund; Local Government Information Unit; NAHAT Health Authority Council; NHS Executive; National Institute for Social Work; Office for Public Management; Patients Association; Rehabilitation Resource Centre; Riverside Community Healthcare NHS Trust; Royal College of Nursing; Royal Free Hospital School of Medicine; Sheffield University; Standing Conference of Ethnic Minority Senior Citizens; Survivors Speak Out; Westminster Borough Council; York University .

Health and social care futures

– *Chris Gostick*

Redrawing the boundaries or preparing for the millennium?

This is the debate of the next decade. It raises big and complicated issues which demand big and complicated answers. So far, we are in danger of fiddling about on the edges of the health and social care divide rather than seeing this as a debate about the sort of society in which we want to live in the millennium.

Great pressure

The problems we are witnessing now have been evident in trends within community care services for a long time. The reforms brought about by the NHS and Community Care Act 1990 have not caused the difficulties, they have merely exposed them for all to see. As we consider the future of the NHS and long-term care, it is vital that we also look at acute care, recognising that this is a great driving force in the NHS. Advances in technology, people's expectations of cure, and better communications about possible treatments all combine to put great pressure on the health service, and there appear to be few countervailing forces stemming the demand for acute care. What we can see, however, is users and carers getting more involved in the debate and raising questions about the role of the NHS in long-term care. We should encourage this involvement.

Practical responses

Before we can advance with any confidence on possible solutions, we should take the opportunity provided by the 1990 Act to learn more about the ways in which boundaries between health and social care can be and are being redrawn by GP fundholders and social service care managers. As they work together, focusing on individual needs and practical responses, they may be able to show us more efficient ways in which we might use the resources already available. We also need to know more about the effectiveness of both health and social care services and the impact they have on people's quality of life. In addition, it would help to have a better notion of what is actually spent on long-term care at the moment.

In any future scenario regarding long-term care, it will be important to shift the NHS back to health care, moving it away from being a sickness service based on hospitals. Preventive services will need to be emphasised, and we should discuss openly the role of acute hospitals and the amount and type of acute care that will be provided.

Local authorities will have to draw back from focusing support on smaller and smaller groups of people if they want to avoid becoming a poor law service by the end of the decade. Preventive services accessible to wider populations will be difficult to achieve, but possible with vision and leadership.

Organising services around people

The NHS will have to put its own house in order, tackling fundamental problems in the way services are structured. It does not make sense to organise services in acute, primary and community divisions. Services should be organised around people, with the commissioning process achieving integrated service responses, thereby encompassing all three kinds of care. It will be right to focus on GPs and primary care, and to rethink what their role in long-term care might be. We should also look closely at other aspects of primary care, such as the community pharmacist and the role of therapy services and alternative medicine.

There is a possible case for integrating health and social care agencies. Such a move would certainly enhance democratic accountability within the NHS, particularly if local authorities were to be made responsible for health and social care services. But equally, some reform of local government would be needed to ensure proper accountability. However, integrated authorities will not solve the problem. No one is suggesting that local authorities should commission acute health services, so a boundary problem will remain, which might be less easy to manage than the grey area on the boundary between health and social care. In addition, there is no guarantee of better collaboration between health and social services when they are located in one organisation.

The contribution that housing makes to long-term care must be addressed seriously. Indeed, we need to move towards a comprehensive, co-ordinated social policy that encompasses employment, education, housing, income support and health and social services. The wider focus will make it clear that health and social care agencies are actually small players in a very complex scene. Only then will the debate have been widened in a way that does justice to the complex issues surrounding questions about the NHS and long-term care. ❑

Discussion

Discrimination in health care

The current health care system discriminates against older people. People with heart failure and incontinence are no longer seen as needing medical or nursing care; they are defined as needing 'social care', shunted away from the NHS and expected to pay for services. This does not happen to younger people in work who undergo elective surgery. We ought to be questioning the assumptions behind this and asking why anyone with either an acute or chronic condition should be expected to pay for the care they need.

The care continuum

Older people have a wide variety of needs, ranging from those living alone and needing 24-hour care to those with moderate disabilities, living with a daughter or son. It is possible to enable even severely disabled people to live in their own homes, where sufficient resources are available, and there is a willingness to invest in developing skills among care staff. At the same time, it will not be possible to do away entirely with institutional care.

Questions of finance

Insurance schemes are not appropriate for people using psychiatric services. They are caught in a vicious circle, where they cannot get jobs enabling them to make insurance payments and where insurance policies will not cover anyone diagnosed as a schizophrenic. They also find it hard to secure mortgages and are therefore in no position to sell their homes in order to finance their care.

Social insurance schemes are a form of taxation but are never portrayed as such to the general public. It is not surprising, therefore, that the tone of the debate tends to reinforce a false division between tax and insurance options.

A plea for honesty

The rhetoric of community care fails to acknowledge that the new arrangements provide (and were always meant to) a device for rationing. We do not need a debate; what we need are clear statements saying 'we can't do it all; this is what we can do and this is what you will have to contribute to get it'.

It is puzzling when surveys show that most people prefer tax-based solutions to insurance schemes, when politicians seem to favour the opposite. Are people being entirely honest or are politicians right in assuming that there are no votes in raising taxes? Can we ever expect to see politicians putting forward an honest case for increasing taxation?

A Royal Commission or some such body ought to investigate the problems of long-term care. This would bring out into the open issues which we are only now beginning to address and would lay before the public the real choices that have to be made. ❑

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Ideas for action – *Angela Sealey*

The answer to 'The NHS and long-term care – time for a new deal?' is most certainly 'yes', given the widespread agreement in this debate that the current system for supporting people with chronic illness and disability is not satisfactory. The dissatisfaction takes on different guises, depending on whether we look at the issue as people with ageing parents, as wives, husbands or parents, as workers in or outside the health service, or as service users. Regardless of these differing perspectives and viewpoints, we all seem to have reached the same conclusion regarding the need for change.

In working for change and improvements, it is essential that we recognise and build on the strengths of our current systems. We must not be too gloomy about the future or devalue what we have achieved.

It is not clear what changes could resolve the situations we have been discussing. A number of suggestions have been put forward, but there is no agreement yet on the way forward. This is hardly surprising. We are witnessing enormous changes in society and the welfare state, and it is hard to envisage the future.

However, we have to plan for the future and, in doing so, will have to talk through topics that are taboo. I refer not only to death, disability and dependence, but also to the merits of some increases in taxation. While 'hard' information is obviously essential, we will need to value 'soft' information and commonsense judgements too about, for instance, the contribution families make in supporting disabled or elderly relatives and the differences that community services can make in their lives. Some other countries invest far more than we do in community care services. We need to understand what this means, for instance, in terms of prevention, or maintenance of reasonable health and activity, and what we might learn from such different practices. We need to distinguish between our aspirations and reality; for we must be clear not only about what we want but what we are prepared to provide and at what cost.

As the debate progresses, we need to think more boldly, unpicking long-held assumptions and using our imagination more daringly. We also need to be much more open about all the issues involved, raising them in new contexts and listening to and hearing what patients and their carers are saying.

There are no quick-fix or magic solutions: we are dealing with service issues that need to be seen in the context of our society and its economic, social and political systems. What is important is that the great debate has begun and that we are beginning to glimpse the power of individuals to claim what they want and a new willingness to listen to those claims. ❑

This debate was the second in a series organised by the King's Fund. It was held in September 1995 and chaired by Nicholas Timmins, Public Policy Editor of *The Independent*.

Edited by Janice Robinson, Director of the Community Care Development Programme, King's Fund.

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SUMMARY

- The debate was opened by Professor Alan Walker of Sheffield University. In 'Policy Perspectives', he argues that the current crisis in long-term care has been caused by long-standing deficiencies in the organisation of services exacerbated by the recent introduction of a quasi-market in the NHS. He calls for a new vision for long-term care where older people and their families can expect an end to paternalism and discrimination; the security of services financed through general taxation; and the reduction or removal of unhelpful organisational divisions between health and social care.

- In 'Family Experiences and Expectations', Jill Pitkeathley, of the Carers National Association, goes on to describe the disillusion and disbelief felt by many people when they find that the care they expected to be provided free of charge by the NHS is no longer available. She argues that current problems in long-term care raise fundamental questions about the respective duties and responsibilities of the family and the State. She calls for a new deal which would benefit caring families.

- Looking at the NHS from a different angle, Pat Gordon, of the King's Fund, points out that primary health care services make a major contribution to the support of people with long-term care needs. She argues that the UK's unique primary care system has the capacity for managing changing patterns of illness and disability and for providing new models of service offering alternatives to institutional care. She urges more proactive development of primary care so that it can achieve its full potential as a keystone of community care.

- Chris Gostick, of the NHS Executive, examines tensions on the health and social care boundary. He urges local authorities and the NHS to pull back from a future featuring 'poor law' social services operating alongside a universal health service driven by acute care pressures. He sees the creation of integrated health and social care agencies as offering no convincing solution to boundary conflicts, arguing that long-term care has to be seen in the context of a comprehensive social policy encompassing employment, education, housing and income support as well as health and social services.

- In conclusion, Angela Sealey, of the National Association of Health Authorities, proposes that the debate must be taken further as we are contemplating no less than fundamental changes in the welfare state and in society at large. She notes that, in planning for the future, some current taboos will need to be broken. This might mean bringing into the open our concerns about death, disability and dependence, or it may simply mean daring to discuss in public the merits of tax increases. The way forward requires imagination and hard-headed realism, as the challenge is to identify not only what we want but what we are prepared to provide and at what cost.