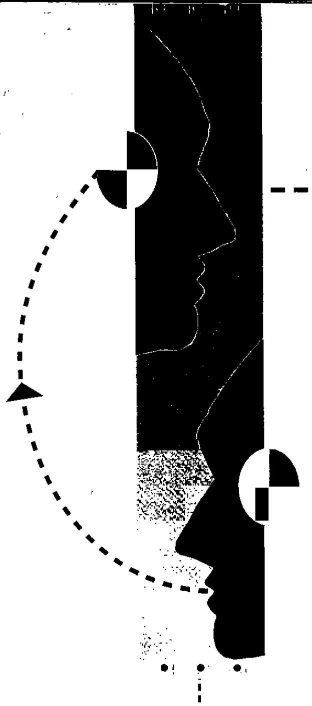

# COMMUNITY CARE DEBATES

## DEBATE 1

## COMMUNITY CARE: A QUESTION OF RIGHTS

April 1995

Would ill or disabled people and their carers be better off with a community care system guaranteeing them rights to services? This question was posed at a recent debate organised by the King's Fund and the National Institute for Social Work.

The question of rights challenges a community care system which feels like a lottery to many elderly and disabled people and their families. The idea of increasing people's rights to services attracts interest and support across a wide spectrum of public opinion. But support for radical change in community care begins to break down when it comes to defining what those rights should be and agreeing how a rights-based system would actually work.

The debate was opened by **Nasa Begum** of the King's Fund and the National Institute for Social Work. In "Disabled People's Perspectives", she argues that elderly and disabled people want a different kind of community care, one that provides them with the essentials of daily living. Ms Begum argues that a rights based system would enable active citizenship and end the paternalism and segregation which disables people. Both procedural rights, such as the right to information, and substantive rights, to independent living must be examined seriously.

**Raymond Plant**, Master of St Catherine's College, Oxford develops the argument that rights and entitlements are, from politically contrasting views, seen as ways of constraining welfare bureaucracies which have a tendency to grow and act in their own interests. Raymond Plant cautions that if rights are to mean anything they have to be enforceable and can not be withheld because of scarce resources. This would present a major challenge to the present system of public administration.

**Jane Winter**, from the Public Law Project, in "The Legal Perspective", argues that a lack of clarity about rights and responsibilities in community care is at the heart of problems faced by authorities and by disabled people themselves. She maintains that the current legal framework permits wide variations in local policies and practices and this is leading to discontent and to legal challenges. She warns of a "happy hunting ground for lawyers" in the years ahead.

Looking at the introduction of community care reforms as Controller of the Audit Commission, and as a former deputy chief executive of the NHS, **Andrew Foster** points out that the impact of the reforms are only now beginning to be felt. The reforms have removed an entitlement to residential care through the system of social security payments, replacing this with a new regime of assessment and discretion. He argues that expectations of better community services have not yet been met, and while it will take time for service improvements to show through, the new system is forcing authorities to be much more clear and open about what they will provide and who will be entitled to provision.

**Sir William Utting**, Chairman of the National Institute for Social Work proposes in summary, that the Government should resolve to embark on a comprehensive revision of the law relating to community care, while acknowledging that the issues of substantive rights are more problematic than the argument for procedural rights, over which the Secretary of State has considerable discretion. Until the Government faces this challenge, the courts will continue to expose individual injustices, while authorities and disabled people will continue to be unsure about the boundaries of their obligations and entitlements.

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## DISABLED PEOPLE'S PERSPECTIVES - NASA BEGUM

When talking about a right to community care, we are not referring to luxuries of daily living but focussing on the fundamental requirements of being able to live in the community i.e. getting washed and dressed, eating, moving around etc. Essentially, discussions about a right to community care are about a right to many of the things non-disabled people take for granted.

Disabled people do not have rights to services at present: rather, local authorities have duties to provide services. Both the Disabled Persons' Act and the NHS and Community Care Act do no more than provide a procedural framework for the exercise of those duties. The position is slightly different with health, where there is in principle a right to care that is free at the point of delivery.

In the experience of disabled people, services are inflexible and fragmented, bedevilled by confusion over what is health and what is social care. They are also very variable, and depend substantially on where you live and who does your assessment. Services tend to be paternalistic, philanthropic, disempowering and inequitable. The welfare state has turned disabled people into passive citizens. Community care services are themselves disabling, segregating people and withdrawing their right to control over their own lives.

Disabled people want to live as full members of society, and for that they need a rights-based system - the right to choice, control, self-determination, autonomy and equity of treatment. Community care services could promote active citizenships, if they furnished the essentials of daily living.

A rights-based system would confer broad general rights, a set of entitlements, a framework for enforcing entitlements, and resource allocation separate from service provision. There would need to be independent advocacy, an independent appeals procedure and strong user involvement in the running of services.

Essential procedural rights include the right to information, to self assessment, direct access to expert advice, independent advocacy and appeals and access to legal redress. These would be valuable, but the core issue is substantive rights: rights to independent living, cash payments instead of services if desired, more user-controlled services, access to health care, accommodation and accessible environments. There are no rights to services in the Civil Rights Bill, which simply prohibits discrimination in goods and services.

It is important to acknowledge that a rights based system will not guarantee good quality services, but would tackle problems in terms of access to services.

A rights-based approach does create dilemmas. Statutory rights may not yield substantive rights to services. Such rights could be minimalist and too prescriptive. They would entail a major shift in the role of health and social services professionals, who would no longer be judge and jury but would instead provide information, and match services to people. There would be additional costs, but there are also costs to preventing people from participating fully in society. There is no evidence to suggest that giving disabled people rights would open the floodgates: on the contrary, people tend to police themselves and make fewer demands than professionals expect.

**Issues which bear further consideration are:**

- How could a rights-based system promote active citizenships? Community care services are vital to daily life - they are not of the same order as libraries and some other local authority services.
- What is the cost of **not** empowering disabled people? What are we wasting in terms of human potential as well as resources?
- What would it mean to offer people a reasonable quality of life? What would be included and how much would it cost?
- What is the right balance between entitlements and discretion?
- And who decides?

## POLITICAL PERSPECTIVES - RAYMOND PLANT

Rights turn on philosophical points, but their context is political. One might ask why rights have become important in recent years and what forces have brought this about at both ends of the political spectrum?

The Right is distrustful of bureaucracy, which tends to deny the public choice. People in the public sector are seen to be motivated by behaviour which maximises their own interest, but, unlike in the private sector, do not have the constraint of the prospect of bankruptcy. The answer would be to take these services to the market, but since these are non-marketable public goods, that is not feasible. Rights and entitlements are therefore seen as a market analogue, and a way of constraining bureaucratic behaviour.

On the Left, there has been a collapse of confidence that bureaucratic behaviour can be regulated by other bureaucracies, and a collapse of faith in democratic accountability. Asymmetry of motivation, information and professional skills between professionals and democratically elected representatives results in a lack of accountability within bureaucracies. The answer is to empower the consumer directly.

So part of the political context is a critique of the nature of bureaucracy.

Furthermore, rights must be based on solid foundations, but these are disputed. If rights are based on needs, how are needs determined? Needs seem to be an illusory notion, and many economists dispute their definition. Some say that they are merely wants that you don't pay for.

Rights also have correlative obligations. If you have the right not to be killed, I have the duty not to kill you. Can rights exist without accompanying duties and if rights are rights to resources, how are the duties to be defined?. Rights are also based on contract: they do not always arise out of status.

Enhancement of rights would change the nature of public administration. While public authorities have duties to provide services, this does not yield individually enforceable rights. We do not have an individually enforceable right to the services of the police or to those of a doctor. It is also argued that there cannot be a right to a scarce resource. Rights must be enforceable; there cannot be substantive rights to a scarce resource.

Since a move towards rights would change the whole basis of government, the argument tends to be about procedural rather than substantive rights. Procedural rights are important, but they are different. There are two possible approaches to dealing with this problem: either we accept that we do not have substantive rights, or we say we do have such rights but they are not enforceable.

If rights to services were enhanced, they could be realised in a variety of ways - e.g., through cash, vouchers or services. A rights-based approach would not necessarily result in increased services or more bureaucracy.

## THE LEGAL PERSPECTIVE - JANE WINTER

The Public Law project exists to enhance access by disadvantaged people to public law remedies such as to judicial reviews. It has been concentrating for the last year on community care.

The NHS and Community Care Act 1990 provides a framework for the assessment of need for community care services and for the provision of such services, but it is not a comprehensive piece of legislation and can only be fully understood by reference to numerous other statutes and regulations, as well as departmental directions and guidance. Need for services under the Chronically Sick and Disabled Persons Act 1970 is assessed under the separate procedure contained in the Disabled Persons (Services, Consultation and Representation) Act 1986.

Key new duties placed on the local authority under the 1990 Act include a duty to assess need for community care services, to consider provision of services, to establish a complaints procedure and to publish a community care plan, but these provisions are both vague and flawed. They confer very few rights, though they may raise many expectations.

Delays in obtaining assessments and disputed assessments are likely to give rise to numerous complaints. The new regime does not address the issue of resourcing services, and the question as to whether lack of resources can excuse a failure to provide a service will lie at the heart of many legal challenges, some already in the pipeline. Both service users and local authorities need to know the answer.

Since the legal framework is so loose, policies and practices will vary considerably from one local authority to another, and people with identical requirements are likely to receive different services depending on where they live. This too is likely to give rise to discontent and legal challenge. The main remedy when things go wrong is the complaints procedure, but this has a number of unsatisfactory features built in to it, notably the length of time it can take, the fact that complainants are not entitled to legal representation and the fact that the findings of the procedure are not binding on the local authority.

**The main areas of confusion are:**

whether the matter in question comes under the NHS and Community Care Act, or whether it comes under the Chronically Sick and Disabled Persons Act (some services required may come under neither). It is at present unclear whether CSDP services come under the definition of community care, and the answer is significant because it determines whether users will have to pay for a service or not.

- whether the service in question is provided under a statutory duty or whether the local authority has discretion in the matter. The likely success of any legal challenge may depend on this. It seems increasingly likely that discretionary services will get squeezed out by lack of resources.
- who is responsible for providing the service? In a situation where many services are provided not by the local authority itself but by a third party, it may not be clear who is legally responsible for deficiencies. This problem is particularly acute in relation to the health service. The local authority is responsible for ensuring that a person's health needs are assessed, but there is no corresponding duty on the health authority to provide that assessment. Furthermore both the Act and the accompanying guidance are silent on the question of what happens if the social services department assesses someone as needing a health service and the health authority disagrees or refuses to provide the service. Such problems are particularly acute when it comes to the discharge of hospital patients and the long term care of people who are mentally ill. A similar anomaly exists with Housing Departments.
- Is it reasonable that services should vary with geographical location? A prison officer with a disabled daughter has moved from one area of the country to another; the services available in the new area are much less comprehensive. Why should the level be different? There is certainly no level playing field between the different parts of the United Kingdom, where different legislation applies. In Northern Ireland, for example, there is no right to assessment - although ironically the services are better.

In short, people's rights to community care services are unclear and are likely to provide a happy hunting ground for lawyers in the years ahead. Ultimately it will be the courts and the politicians which determine these rights. Legal responsibility for the provision of community care is very unclear, to the serious disadvantage of disabled people and other would-be users, and it urgently needs clarification. Social Services Departments may have to become more rights oriented and social workers may have to enhance their traditional role of acting as advocates for their clients.

## THE MANAGEMENT PERSPECTIVE - ANDREW FOSTER

The genesis of the NHS and Community Care Act came from a number of different sources but attracted considerable consensus. It amounts to a massive set of managerial, resource and cultural change, and its implementation has only just started. Few people on the receiving end will have seen any benefits; we are still a long way from the expectations raised by the Act. There is undoubtedly scope for potential improvements, but many are not yet happening, and the legal definitions present something of a minefield. Assessed needs and eligibility criteria are not necessarily congruent.

At the heart of the changes, progress with community care should mean sensitivity in identifying local needs, flexibility in services to meet those needs, and responsiveness through innovative service delivery. There is at least an aspiration to view development from the service users' point of view.

How well is it going? It is difficult to make firm comparisons, since the data from before the changes was poor. Budgetary control seems to be reasonable. Local authorities held their act together, and the Department of Health won more resources from the treasury than expected. On unmet need, local authorities have estimates, but these are not fully costed. There still needs to be a better sense of who is not being provided with services. Joint working between health and social services has worked well in some places, but the current situation exacerbates cost shunting and puts the user in a dilemma. This is a key area for further work. The system of delegation, which is supposed to bring the resources closer to the consumer and enable responsiveness, should push money and financial control down the organisation. This is a difficult area for local authorities, against the grain of their usual way of working, and hence also a major issue.

Different aspects of the changes are working well in different authorities - the picture is multi-dimensional and complex.

There are also multiple motivations at work. For the voluntary sector, the changes are a major chance to innovate and develop services. Central government wanted the changes for moral reasons and also to contain expenditure and ensure financial control. Local authorities have the toughest job; they have to sustain the confidence of the electorate while working within resources. They were, however, pleased to have the control of services confirmed. Health purchasers also face massive change, since what is required is an integrated approach to planning. So all players in community care have different expectations.

**Key points for the next stage of development are:**

- How can we integrate these different perspectives? This will be different and we are still a long way off.
- What is the relationship between the individual and the state with its public provision? The changes included the removal of an entitlement to residential care through the social security system, replacing it with a process of assessment and discretion. This major change happened without public debate, and people are only now realising that it has happened. The future of long term care for older people is a major unsolved issue which will be critical in the coming years.
- What should be the proper balance between care that is free on the NHS and chargeable social care?
- What are the rights of the individual?

These issues represent a journey of discovery for both Left and Right and will require tough thinking over a long period.

## Discussion:

### Legislation and the Need for Clarity

There is real confusion about the extent to which we do have rights at present. For example, we act as though we have a right to be treated by a GP. In fact we have the right to be registered with a GP, but treatment depends upon the doctor's assessment. We actually have very few individual rights, but we make assumptions about the kind of treatment we are entitled to. It is only when our expectations are disappointed that we realise that we have no rights.

It is, however, not universally true that legislation that confers a duty on public authorities provides no individual rights: it depends on the wording of the law. The Chronically Sick and Disabled Persons Act does furnish individual rights, which creates an opportunity to challenge decisions. Perhaps we should adopt an incremental approach to rights, building on what we have already got.

The present confusion is unhelpful. We need a clearer legal framework and better procedural and substantive rights, if only for the sake of equity and equal treatment for individuals. It is not just a matter of the law itself: Department of Health guidance and directions add further confusions and contradictions. Information from local authorities needs to make clear to the public what services may be available and what the criteria for eligibility are.

Local authorities are moving in that direction: explicit rationing is being put into place; scarce resources are targeted - not yet irrespective of ethnic origin or of income, but we are getting to the point of having much more explicit systems and hence more enforceable rights. Gatekeeping itself must be transparent and challengable (and by something stronger than the complaints system). Written agreements, explicit criteria, and unit costs give more power to those who do get through the gate. Beyond that, it is debatable whether people would be better off with more explicit rights. Some would, perhaps, but not all, and not yet.

It is not just a matter of rights but of attitudes and expectations as well; part of what will create change is educating the assumptions we make about our entitlements.

### Rights and Scarcity

The problem is fundamentally one of how we can have rights without the resources which would enable those rights to be realised. The community care changes were accompanied by arcane financial transfers. It may possibly be the case that there is more money around, but estimates of what was needed were based on flawed assumptions. The research on which the changes were based was centred on a very specific population of elderly people living alone. Assessment and care management now apply to a very much wider group of people. Most older people were previously getting nothing at all: how could community care be expected to make a difference to them without taking services away from others unless the financial allocation recognised that this was a new population?

What are the administrative implications of a rights-based approach where there are cash-limited budgets? Local authorities would be in a similar position to that which they are in when they provide housing benefit.

Community care as it presently stands is a lottery; scarcity leads to the language of priorities. Section 20 of the Race Relations Act prohibits discrimination in the provision of services, but elderly people from ethnic minorities are still the forgotten people. Civil Rights legislation in the USA and here is about the prohibition of discrimination, not entitlement to services.

Is the motivation behind the discussion of rights really a desire to improve the quality and range of services? And if so, should that be our focus?

### The Case for Procedural Rights

The issue is really one of changing the behaviour of those who allocate scarce resources. There are many ways of changing behaviour: through financial incentives, through persuasion and so on. Increasing procedural rights would be an easily available and accessible way of changing behaviour. One obvious procedural change would be to give people the right to an individual written care plan - quick, clear and accountable. That would be a clear gain, and there is no reason why it could not be introduced by Ministerial direction tomorrow.

The problem of scarcity remains, however. Should there be a procedural right to a fair allocation of such resources as there are? What is the basis for a just distribution between individuals?

### Beyond Rights

The issue is not just one about substantive or procedural rights. One major problem for people who use mental health services is professional arrogance, especially from those who have undergone health and social services training. The tendency for such staff to believe they know better infringes rights to self determination.

What people need is the right to a **choice** of services. The Mental Health Act gives professionals the right to deprive people of their liberty, to force medication on them, to dictate how and where people will live. What is needed instead is the right to services that will do some good.

Furthermore, much of our current legislation contains entrenched age discrimination. Mobility allowance, for example, is only available to disabled people under retirement age. Different charging policies are in operation in many authorities for those over and under sixty five, creating grossly inequitable situations. Access to transport and housing are part and parcel of what people should be entitled to expect as ordinary members of society.

The focus on rights is a hopeful move; it indicates that we are looking for a new way of thinking about the society we live in. In Eastern Europe, they are also trying to recreate society; the focus there is on responsibility to each other. In New Brunswick, there is a right to education but also a right for all children to be educated alongside others.

Instead of talking about rights to "services", we should be thinking about the right to an ordinary life, and defining what that means. We should be getting out of the welfare/social care frame of reference and considering instead what care and support is necessary to enable ordinary living.

## IDEAS FOR ACTION - BILL UTTING

Would enhanced rights help people who need services to get a better deal? It is still unclear; but it has been useful to have a rational discussion. We should bear in mind that in many quarters, ignorance and prejudice against disabled people are still widely displayed, as a recent article in the Spectator made abundantly clear.

Perhaps the most important thing is to continue to stimulate intelligent discussion, both in Parliament and elsewhere. What has emerged from this debate is that there is no solid intellectual foundation to substantive rights unless for the whole population; but that procedural rights are both important and attainable, and the Secretary of State has considerable powers to act on this matter.

The major target should however be a comprehensive revision of social services law for adults. The evolution of Caring for People contained a strong ethical thread, which was not sustained either by a comprehensive legislative background or by the necessary resources. We have been told that it would take a legal genius to pick their way through the various Acts currently governing our services.

There is no underlying legislation to enable community care policies to be attainable. The legislation spans fifty years, from the National Assistance Act of 1948, when the social and economic circumstances of the Beveridge era prevailed. Some legislation still has echoes of the Poor Law; other parts have arrived on the statue book by happenstance, through private members' bill at well-judged moments; some of it, notably the Disabled Persons' Act, has been emasculated after it was passed. As it stands, it discriminates between categories of people; some people can be said to have rights to services, other are reliant on the exercise of local authority powers alone. These differences between older, disabled and mentally ill people need to be eliminated in the interest of equity.

Revising the legislation is probably the last thing that government will want to do, but that is what is needed. The courts will progressively expose the illogicalities in the current arrangements. The Health Select Committee should take up the cause. And disability organisations should mount a common political campaign.

There may well be scope for increased procedural rights, and those are worth a try, but what we should be aiming for is revised legislation for all people affected by community care.

**This debate was the first of a series being organised by the King's Fund. It was held in January 1995 and was chaired by Robert Maxwell, Secretary and Chief Executive of the King's Fund and Sir William Utting, Chairman of the National Institute for Social Work. Participants in the debate came from a wide range of organisations including the Department of Health, research institutes, NHS boards and trusts, local authorities and voluntary organisations.**

Edited by **Tessa Harding,** *National Institute of Social Work* **and Janice Robinson,** *King's Fund Centre*

People from the following organisations attended the debate.

Association of County Councils
Association of Metropolitan Authorities
Audit Commission
City University
Department of Health
Greater London Association of Disabled People
Hillingdon Health Agency
Institute of Health Service Management
Institute for Public Policy Research
King's Fund
Local Government Information Unit
MIND
National Association of Health Authorities and Trusts
National Insititute for Social Work
NHS Executive
North and Mid Hampshire Health Commission
Nuffield Community Care Studies Unit
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Survivors Speak Out
The Baring Foundation
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