

**OUR VOICE IN OUR
FUTURE:
SERVICES AND
SUPPORT**

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**Shaping Our Lives/
National Institute for Social Work**

Our Voice In Our Future: Services and Support

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Summary

Introduction

Our Voice In Our Future is a project to give people who use services a say in how they change in the future.

There are three booklets: one on benefits, one on mental health services, and this one.

The booklets tell you what changes have happened already and the changes that are happening now.

We want to hear what everybody has to say about these things.

We are also talking to people in two areas to find out more about what they think.

Not everyone will agree with what we say but we think that it is important that users have a bigger say than before.

Our Voice In Our Future is part of a project called Shaping Our Lives. The Joseph Rowntree Foundation gave us the money to do this work.

Support and services

The welfare state has two types of services: medical, which is provided through the National Health Service – the NHS, and social care, which is provided through social services. Social services also work with private companies and charities.

People's families give most social care.

The NHS

During the 1980s changes by the Conservative government led to there being more managers in the NHS. Many people said too much was being spent on management and more needed to be spent on services.

The Labour government has changed this and is now setting up what are called primary care groups. These should allow doctors to decide how money is spent. They should also help the NHS to work better with social services.

However, there is still concern about how much we spend on health services and many people still have to wait a long time for treatment and operations.

Most similar countries spend more on health services than Britain does.

Social care services

The biggest change in social care has been the introduction of community care.

Community care developed slowly during the 1980s with people being moved from long stay hospitals into the community. This led to the National Health Service and Community Care Act in 1990, which made councils responsible for arranging community care from 1993.

Anyone who needs a service can ask for an assessment, but many people are kept waiting for assessments and they are often used as a way of stopping too many people getting services.

Another important change was the Children Act in 1989. It makes social services consider what is best for children whenever they have to deal with families.

Funding

Funding has been a problem for social services for many years.

Funding for social services is complicated. Some of the money comes from councils from what people pay in council tax. Some of the money is paid to the councils by the government. More and more money is being paid to councils by people who get the services.

It is estimated that funding for services has gone down in recent years while demand for services has gone up.

Many people believe that community care needs a lot more money than it gets at the moment. Councils keep people waiting for services. Some councils have changed the rules about who can get services, some have set limits on the amount of money they will spend on individuals.

Some service users have gone to court to try to get services but the courts say that councils cannot provide services where they do not have the money.

Charges for services at home

Charging for services like home helps and day centres seems like a new idea but it started happening many years ago. What has changed is that the charges have gone up a lot because of councils being short of money.

Some service users call this a tax and say charges are unfair. It is especially unfair that people in different areas pay different amounts of money for the same service.

Charges are stopping some people from using services.

People say that there should be more discussion about having to pay for services.

Long term care

Many people do not agree with having to pay for places in residential homes.

Before the current system for community care started in 1993 residential care was paid for from social security. Councils are now allowed to make people pay for residential care.

More people can pay for residential care because they have houses that they can sell. Some people say the reason for community care was to reduce what the government has to spend on residential care. It had gone up a lot in the 1980s, from £39 million to £2,575 million.

Older people are particularly upset about having to pay for residential care. They believe they have already paid for it by paying taxes.

When Labour was elected as the government in 1997 it set up the Royal Commission on Long Term Care to work out the best way to pay for residential care.

It said that care should be free and that people should just pay for their accommodation. The government does not agree with this but has not said what it will do.

User involvement

The Community Care Act tells councils that they must consult people who use services about the support they receive and groups of service users about planning services.

This has been very good in some areas but very poor in others. Some people feel they are not listened to and have bad experiences, which are very off-putting.

Everyone says they want user involvement, but more needs to be done to make it happen.

Direct payments

Direct payments have been a big victory for service users.

They mean that people can be given money to arrange their services instead of getting them from the council. Not many people can get payments at the moment but the government is working to make sure more people can get them.

This will include older people and people with learning difficulties.

Some people are concerned that direct payments might undermine social services.

Alternative ideas

These are some of the ideas people have about how to make things better:

- Everyone should have a right to services which are based on what is called the social model of disability.
- Services should be planned to give the results that users want.
- There should a new tax/national insurance scheme to pay for long term care.
- Direct payments should be available to all service users so they can be independent.

Introduction

This booklet is part of the Our Voice In Our Future project which aims to give people who use services and receive benefits provided through the welfare state a say in the future.

It is one of three booklets which will give people background information on three key areas of discussion on future social policy. This booklet covers issues about services and support. The other two deal with benefits and mental health issues.

The booklets aim to help people think about the changes that are taking place and being planned to the services and support that are vital to their lives. The people running Our Voice In Our Future believe that people who use services and receive benefits have some of the most important expertise on these issues. We believe that any plans or changes that are made without talking with us first are unlikely to work or improve things.

Each booklet ends with a section called Issues for Discussion – you can use this yourself, or with friends and people that you meet or work with, to think about what you want to say about these issues.

We also hope that wherever possible, organisations that represent service users will send us their views on these issues (where organisations have existing policy documents on these issues we would be pleased to receive them).

As well as publishing and distributing these leaflets, Our

Voice In Our Future is working directly with two local user-led organisations to hold discussions with different groups of service users to get a detailed picture of their views on the future of services and support.

When we have finished meeting and talking to people we will be writing a report that will be used to tell the government and MPs and others who influence policy changes.

There are many points about the future of services and support from the welfare state being debated at present and it's probably worth noting, as one writer has observed,¹ that there has never been very much agreement about the welfare state except in the years after World War Two when the system was being set up.

Our Voice In Our Future is unlikely to break 50 years of disagreement but it can mark the start of a stronger voice for users in this continuing debate.

Our Voice In Our Future is being run by Shaping Our Lives, a national project which works to show the importance of involving users of services in the planning and running of the services that they use. The work is being funded by the Joseph Rowntree Foundation as part of its Shaping Futures programme.

Michael Turner, Project Worker, Shaping Our Lives

1. Support and services

The welfare state provides a range of services and support to people in need. The most obvious example of this is the National Health Service which provides medical support paid for through taxation.

In addition to this there is a range of other services that are generally referred to as social services or social care. They are generally provided for people such as disabled people, older people, people with learning difficulties, mental health service users and survivors, children and young people, and people with drug and alcohol problems.

As well as the type of support being provided, health and social services differ in that one is a national service and the other is provided through local councils. Social services are also more complicated in the range of organisations involved, with many services being provided through private companies and others by charities. The vast majority of social care is still provided through families.

The NHS

Changes in recent years

During the early 1980s the Conservative government introduced significant changes to the way the health service was run, creating what was called the internal market, which meant different parts of the health service paying each other for services.

Critics said that this led to too much bureaucracy and too many managers, and that this took resources away that should have been spent on services. The system was also seen as unfair as some GPs became 'fund holders' and were able to get hospital treatment ahead of patients registered with other doctors.

The Labour government abolished this system and is in the process of reorganising the administration of health services into what are called primary care groups. These groups are intended to put GPs at the centre of the decision making process and to encourage cooperation between health and social services.

Despite the changes, there is still concern about issues like the time people spend on waiting lists for hospital appointments and operations and the availability of drugs and treatments that are said to be too expensive.

The government has put new money into the health services, but waiting lists remain lengthy and some treatments are still said to be too expensive. These are issues that have been with the NHS since it started.

Some people say that there will always be limits to what the health service can do, but these limits are set by how much the government decides to spend on the health services and on what parts of the health service they spend it on.

The amount of importance attached to health services can be seen by comparing spending in different countries, and Britain spends a smaller proportion of its total spending (what economists call the gross national product) than most other similar countries.

The proportion has gone up in Britain but it has gone up even more in other countries. Britain was the eighth biggest spender on health services thirty years ago, but by

1993 it was twentieth and spent below the average proportion that other European countries spend.² The flu crisis of the winter of 1999/2000 brought promises of a significant boost to NHS funding that will bring spending in Britain in line with other European countries.

One of the key concerns about funding has been the differences in treatments people can get in different areas, with some health authorities running out of funds and occasions when people have been refused certain drugs or treatments because of the cost involved.

It means that while the health service is national and the principle is that everyone should get the same treatment, this does not happen. This has particularly affected people living with HIV/AIDS and people with other types of impairment that can be treated with expensive drugs.

The current government is attempting to change this with actions like setting up a new medical committee to decide which drugs should and should not be available on the NHS.

The government is also trying to bring private money into the health service with its private finance initiative for getting new hospitals built. This scheme will involve hospitals being built by private companies and rented back by the NHS. There has been some criticism of the idea of bringing money into the NHS in this way.

2. Social care services

Changes in recent years

The biggest change in social services in recent years was the introduction of community care policies. These policies

developed gradually during the 1980s, with the government and local health authorities and social services departments closing long stay hospitals and opening smaller, community based accommodation, and enabling people to live in their own homes.

These policies led to the Community Care Act of 1990, which came into effect in 1993. Many of the changes brought in by this Act were about the way services are delivered rather than the actual service people receive.

The report³ that provided the basis for the Act said that the bulk of care has been and is always likely to be provided by families, so in effect this means that services are designed to support unpaid family care. Some people have said that this means that we have care by the community rather than care in the community.

The key change brought in by the Act was to make the social services departments in councils responsible for assessments and arranging services. They did not necessarily have to provide the service themselves – they were encouraged to buy in services from private agencies and charities. Such services include those in the community, such as home care/home help and day centres, and also residential care.

It also means that anyone in need can ask for an assessment and that assessment is meant to be based on the person's needs for services and support. However, many now see the assessment process as a way of limiting access to services, with people being kept waiting for services and only being assessed for services that are available.

Councils also became responsible for inspecting residential homes and other places where services are provided.

Another key change in the law was the Children Act which was passed in 1989. This requires local councils to put the interests of children and young people first in all dealings with families. It says that wherever possible the views of children and young people should be taken into account by social services. Social services have a range of duties in relation to children and young people, particularly covering circumstances where children are taken into care.

Useful statistics

610,000 people in the UK get home care.

670,000 people pay for private home care.

482,250 people are in residential and nursing care.

The number of people in residential care supported through social security rose from 16,000 in 1982 to 281,200 in 1991, with the cost rising from £39 million to £2,575 million. During the same period private nursing homes became the main providers of residential care.

3. Funding

Funding for social services has been very difficult for many years. Councils are under continuous pressure to reduce their funding. Social services are not generally seen as having a high priority with voters and so have often been prime targets for cuts.

Working out the financing of social services is complicated. While it is councils that set the budgets for social services, a large proportion of councils' money comes from the government. Since the introduction of

community care policies in 1993 there have also been special grants from the government to councils for them to take on new duties. When the government works out these grants it assumes that councils will be getting around ten per cent of the cost back through charges to service users.

However, it has been estimated that social services funding has dropped by about six per cent since 1992, and councils have said that the grants for community care have never been enough for the new work they have had to take on.⁴

Despite this, there are clearly growing demands on social services. Older people are the main users of social care services and there is a growing number of older people in the population, so there has been considerable thought about how the growing cost of care for this age group can be met.

Many people believe that community care services are severely underfunded. There is evidence from around the country that councils are trying to restrict the numbers of people who can get services with changes in the criteria used to decide who can get services, and to cut spending through lengthy delays in assessing people for services.

Many councils are also failing to provide all the services that are found to be necessary during assessments, which means that many service users now have what are called 'unmet needs'. Some councils have introduced limits on the amount that they will spend on each service user, with people needing services above the limit being forced to go into residential care.

In some areas these moves have led to court cases being brought by organisations representing service users to try to make councils provide services. The most important of these was brought against Gloucester County Council on

behalf of a disabled man whose services had been withdrawn because the council said that it could not afford to provide them. The court ruled that councils do not have to provide a service where they do not have the funds to do so.

4. Charges for services at home

The current community care system charges for residential and day services. Issues around charges for residential care are dealt with under the heading Long Term Care in the next section.

One of the ways that councils have tried to make up for budget cuts has been to introduce charges for community care services. The government also believes that it is right for councils to charge for services – charges are allowed under a specific law, the Health and Social Services and Social Security Adjudications Act 1983.

While charging seems like a recent idea, local authorities have been charging for services since the early 1900s, and for domiciliary services since the 1940s. Councils also charge for other services such as nursery school education and school meals. It is also worth remembering that there are charges for some NHS services, with sight tests and dental check-ups being paid for by the service user, while prescription charges mean that some medicines cost more through the NHS than they would if bought directly.

In many cases charges do not bring in a significant

amount of revenue, but make a political point. When local authorities took on providing meals-on-wheels services in the 1960s advice from the government said that charges should be made for meals even if this brought in very little income and was expensive to administer.⁵

Charges for home care services and other social services have increased dramatically in recent years and are clearly designed to make up for the limited funding from government grants and the local council tax.

Service user organisations challenge the very fact that the charges are made – they have been called a tax on disability. There is particular concern about the way councils charge people receiving the Disability Living Allowance for care component and the fact that little or no account is taken of the extra costs of living for many disabled people.

Critics also say that charges have been brought in with little or no public debate on the issue and little real consideration of their appropriateness – particularly given that many of the services which people now pay for were previously provided free of charge through the National Health Service.

There is evidence that charges are discouraging people from using social services and causing hardships for those who pay the charges. There is a continuing campaign against the charges.

Even accepting the existence of charges, there is criticism of the different charges made by different local authorities and different policies about who does and does not have to pay. The government is planning to address this (see below) but has not yet indicated how it will do so.

5. Long term care

Long term care is the other area where charging has become a key issue.

Prior to the start in 1993 of the current system for community care places in residential care homes were paid for from social security funding, with the benefits that a person in residential care would have received being paid to the care home. Local authorities did run residential homes before this for older people needing less physical support and residents have always had to contribute towards costs in these homes.

Local councils became responsible for assessing and funding residential care under the Community Care Act and this brought several important changes. With councils becoming responsible for all residential care it meant that everyone going into residential care had to pay what they could afford. This coincided with the growth in home ownership that had taken place in the 1980s, which meant that many more older people than ever before had assets to draw upon and many have had to sell their homes to pay for residential care.

Some critics have said that a major reason for this new system was to reduce the amount of public money being spent on residential care, which had been rising rapidly during the 1980s. The government did transfer money which had been spent on residential care through social security to grants for local authorities, but these grants never kept pace with the growing number of people going into residential care.

Having to pay for residential care from savings or by selling their homes has been a grave concern for older

people. Many feel particularly upset at having 'paid into' the welfare state all of their lives and then having to 'pay again' when they need support.

When it was elected in 1997 the Labour government set up the Royal Commission on Long Term Care to address the situation. The Commission's report in early 1999⁶ recommended that people in long term care should receive free nursing care and just pay for accommodation and living costs. The government has not formally responded to the Commission's recommendations, but is thought to be against providing free nursing care because they believe it would be too expensive.⁷

6. User involvement

One of the most important parts of the Community Care Act was its requirement that service providers consult and involve service users. This requirement applies to individual users in discussions about the support that they receive (the Act also recognises the role of advocates in such discussions), and to groups representing service users in planning and developing services.

It is very hard to assess how successful user involvement has been. There are certainly some areas of good practice where local councils have supported independent service users' organisations, and as a result there has been strong user involvement in services.

However, it is equally clear that in other areas there has been little or tokenistic efforts to involve service users. In many cases users complain of having taken part in consultations without seeing any results or changes from

their participation. In areas where this happens too often service users speak of having 'consultation fatigue'.

It seems that these negative experiences outnumber the positive. Against the background of cuts in services, charges for services, rationing of services, and changes to criteria for who does and does not receive service, it is almost possible to say that user involvement has continued in spite of rather than because of community care.

It might be said that this is because of the strength of user groups and networks which existed before the Community Care Act required consultation, yet there is still a political and professional commitment to user involvement.

In a review of the NHS and Community Care Act carried out for the Joseph Rowntree Foundation in early 1999,⁸ Vivien Lindow, a user-consultant, wrote:

'There are now detailed coherent guidelines for involvement produced by service users and others, and there is no excuse for the continuing failure in community care generally to involve people equally and effectively.'

Despite the lack of an excuse, the failure does continue. It should also be noted that the failure is particularly evident in relation to use of drug and alcohol services, and that the involvement of young people as service users remains at quite an early stage. There are also particular concerns for users/survivors of mental health services with the threat of compulsory treatments.

The question for the future is whether and how user involvement can be maintained and improved.

7. Direct payments

For many people direct payments have been a great victory for service users in the 1990s and may well be seen as the ultimate form of user involvement.

Direct payments are an idea that came from the disability movement, with disabled people seeing being given money instead of services as the opportunity to gain true control over the support that they receive. It took several years of campaigning to get the government to pass a law to allow councils to make such payments to individuals (the Community Care (Direct Payments) Act passed in 1996), although some councils did run schemes through local disability organisations before this.

When a person qualifies for direct payments they are given money by the council instead of a service and they use this money to employ personal assistants or hire staff from an agency to give them the support that they need. The difference about doing this is that they keep control and can decide who gives the support and organise how it happens.

At present these payments have been largely restricted to people with physical impairments, but the government is supporting them being made available to more people with learning difficulties and is going to change the law so that older people over 65 will be able to get payments.

While direct payments have been a victory, this is not to say that there are not problems to overcome. The direct payments law is one that allows councils to make payments – it does not give people a right to them – and many councils are being very slow to introduce them. Many had opposed the introduction of the law. This means

that the number of people receiving direct payments remains relatively few.

There are also concerns that some councils see them as a way of reducing spending on social services. Disabled people's organisations are clear that direct payments are not an opportunity to cut back spending and that they work best in areas where the council funds an organisation of disabled people to provide support and assistance to people receiving payments.

There are some fears that direct payments may undermine social services, and older people have been suspicious about them, seeing the payments as a way of cutting back on spending and saying that they mean proper services may not be there when they need them. Many people also see the idea of having to employ or arrange their own support as a burden that they do not want.

In Australia similar schemes have been opposed by service users, so there could be dangers with direct payments.

8. Alternative ideas

Rights and the social model

One of the key alternative ideas for services is that people should have a right to support rather than having to have their needs assessed. Critics say that there needs to be a universal approach to community care, as there is with health care and education, and that without this there will never be adequate services for people who need support.

It has been said that needing social care is seen as

something abnormal and that this needs to change with our whole view of age, disability, mental health etc.

These ideas are based on what is called the social model of disability. This model is a different way of looking at disability. It shows that 'disability' comes about because society responds to someone having a medical condition or impairment with discrimination and prejudice. In other areas it is the lack of response, such as inadequate services and benefits, that disables people.

This idea was first developed by disabled people but other groups, including older people, mental health service users, people with learning difficulties, and young people who have been in care, are starting look at their situation in terms of a social model.

Outcomes

For some years politicians and people involved in providing services have been saying that services should be 'measured by their outcomes' – that is they should be judged by their results.

These ideas have been developed by a user-led project – the Shaping Our Lives project which is running Our Voice In Our Future – which has put forward the argument that outcomes can only properly be defined by service users.⁹ On this basis it says that services should be planned around the outcomes that people want and that doing this would lead to better and more efficient services that actually deliver what people want.

In looking at outcomes with users the project found that people want a much wider approach to support that addresses all needs and connects community care with other issues around rights and discrimination. People cannot achieve the outcomes that they want with just the services that are currently referred to as 'community care'.

Many people would say that this is a good idea but it is unlikely to happen, with services being cut further and further. However, some people make the point that money is currently spent on services that are not right for most people and that we need to persuade the authorities to put money into the services that people do want.

Some have also made the point that these ideas will certainly not be achievable if people do not speak up for them.

It is also important to note that having better services is not just a case of 'doing the right thing'. There is considerable evidence that providing the right support when it is first needed means that people remain independent for longer and need less in the way of intensive support. Budget cuts currently mean that services are concentrated on people with the greatest needs but this has been shown as being more expensive in the long term.

Paying for services

Another effect of budget cuts has been the increasing charges that users have to pay for social care services. One person who looked at the report of the Royal Commission on Long Term Care has suggested that a further option should be considered.¹⁰

He suggests that all aspects of long term care should be free and that the cost of this should be paid for through social insurance – that is, everyone paying into a government supported insurance scheme, along the lines of National Insurance. The Royal Commission had looked at paying for care through private insurance but found that this could not be relied upon as many people are unlikely to pay for this.

It has similarly been suggested that we need to challenge

ideas around privatisation of services and the efficiency of the private sector over the public sector. Supporters of this view say that we need to restore the idea of 'public service'. They point out the poor services come from both the private and public sector but there seems to be an assumption by the government that the private sector can provide better public services.

Many have asked the question 'how can private companies provide a better service and make a profit where public services do not need to make a profit?' This question is fundamental in looking at services and has wide-ranging implications.

Independence

Most people who need support in their everyday lives identify independence as a key aim.

For many disabled people independence means having control over the services they need and the development of direct payments (see above). The government is in the process of enabling more people, including older people and people with learning difficulties, to take up direct payments.

However, there are other people who would like to see direct payments extended to other service users. Many mental health users/survivors believe that some form of direct payments would be useful for them. They believe it would be particularly useful for their circumstances as it would allow them to use different means of support such as counselling and alternative therapies, rather than traditional services like psychiatry and drug treatments.

It should also be noted that at present very small numbers of users are getting direct payments and that there needs to be more promotion of their availability. Many local

councils have been reluctant to encourage users to take up direct payments.

9. Issues for discussion

The following questions may help you to think about the issues about the future of services and support. Our Voice In Our Future wants to hear from all service users about their views on these issues. You could send us your answers to these questions or write to us about anything else that you think is important.

Send your views to:

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7968. E-mail: sol@nisw2.org.uk*

Should families still be the main providers of social care?

What are the advantages and disadvantages of services being provided by the public, and by the private sector?

Should councils and the NHS be able to provide better services than the private sector?

What do you think of charges for social care services?

Should health care and social care be treated differently?

If there are charges for services, what is the difference between social services and private services?

If there are charges for services, how can they be made fair?

Should people have rights to services and support?

How can user involvement be improved?

Can user involvement be improved when service providers are focussed on reducing costs, restricting eligibility etc?

Are direct payments a good system? What are the good and bad things about direct payments?

How can other groups, such as mental health service users/survivors, benefit from direct payments?

Should more be spent on people who need a little support so that they need less support later?

How should long term care be paid for?

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