

# Rights not write off!

## What disabled people and older people want from social care reform

Scope, Age Concern England and Mencap have jointly published this pamphlet as a speculative ideas document.

**Millions of disabled people and older people rely on social care services every year in order to live independent, dignified lives.**

**For disabled people and older people who need support with day-to-day tasks (such as getting out of bed, going to the toilet, having a shower, getting dressed, cooking a meal, or going shopping) high quality social care services are a condition of equal citizenship.**

**But the social care system is in crisis. Eligibility and charges for vital services are governed by a postcode lottery – so what you get and how much you pay depend on where you live, rather than what you need. Services vary in quality. What’s more, the services frequently do not meet the varied needs of the disabled people and older people who use them.**

This pamphlet is not written to state any fixed policy position. Rather, it is intended to express the views and experiences of disabled people and older people, whilst considering the most significant barriers to creating a fair, transparent social care system – which empowers rather than dis-empowers its users. This pamphlet also identifies some suggested responses for further consideration.



Time to get equal



About cerebral palsy.  
For disabled people achieving equality.

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What disabled people and older people want from social care reform

Jointly published by Scope, Age Concern England and Mencap

## What is social care and why it is important?

Social care covers a very broad spectrum of services provided to disabled people and older people, who need support to carry out everyday tasks. These can include day-to-day tasks such as getting out of bed, going to the toilet, having a shower, getting dressed, cooking a meal, or going shopping.

Social care services can be provided directly by local authorities. Alternatively, individuals can receive cash (in the form of a direct payment or a personal budget) to purchase their own support.

Social care is fundamental to enabling disabled people and older people, who need care and support, to live with dignity and access the same opportunities that non-disabled people take for granted.

High-quality and affordable social care enables disabled people and older people to be empowered and to participate as equal citizens – in education, work, family life, leisure and public life.

An effective social care system is vital if we are to realise independent living for disabled people and older people, and to uphold the human rights of disabled people and older people.

However, in reality, the social care system is in crisis, with many people failing to access the support they need – due to increasingly tight funding and eligibility criteria.

As the number of older people and disabled people increases, so does demand for social care services. This puts increased pressure on a system which is already at breaking point.

The Government recognises these problems and are currently consulting the public on possible solutions. A commitment has been made to reform the social care and support system and a Green Paper will be brought forward in early 2009.

The purpose of this pamphlet is to both highlight some of the key problems that disabled people and older people have with the current system of social care and to propose some solutions to these problems.

## **What do disabled people and older people want from social care services?**

Disabled people and older people want access to the same opportunities and quality of life as any other citizen. When Scope, Age Concern England and Mencap asked people what they thought were the biggest problems with the current social care system, they identified four key issues:

1. Lack of information, advice and advocacy to help make informed decisions
2. The postcode lottery – which means eligibility and charges for services differ, depending on where disabled people and older people live
3. Lack of choice and control over where (and how) disabled people and older people live their lives, to poor quality or inappropriate services
4. The inconsistent (and often prohibitive) cost of services

Underpinning these issues, was concern about the quality of support people currently receive.

### **1. Access to good quality information, advice and advocacy**

Many disabled people and older people who need care and support, do not have access to the information and support that they need to make informed choices about social care. Many people are not aware that they are entitled to social care support, or do not know how to apply for it.

**“I had no idea that I was entitled to any help until a neighbour told me. I had been relying on my daughter for all my support for years until recently, who also works and has a young family.”**

Where information is available, it is often of poor quality or does not cover all the options that may be available. This can result in people having to make decisions without all the facts.

**“It is especially hard to get information.”**

Lack of access to clear information is a big concern. Information services and independent advocates can help disabled people and older people

to understand their rights, explore the options available to them and make (and communicate) their own choices.

Without the support of an advocate, some people (especially those with learning disabilities, communication impairments, conditions such as dementia and complex support needs) have little or no say about where they live or how their support is provided. There is currently a shortage of independent advocacy services in the UK and there is no statutory right to an independent advocate.

Information, advice and independent advocacy also play an important role in helping disabled people and older people get the most out of their social care assessment and in making smooth transitions from children's to adult services, and from adult to older people's services.

For people who want to move out of residential care into more independent settings, an advocate is often an essential part of helping someone make an informed choice.

**“I wanted to leave the care home and live in my own house but I was worried that I would not be able to manage. My advocate talked to me about what I wanted and we found a place where I could live in my own flat but could call someone if I needed help. I was quite scared at first but now I really like it here.”**

As the focus of care policy moves towards increasing personalisation (with Individual Budget pilots being extended across social care provision) information, advice and brokering services will become increasingly important.

### **Some suggested responses**

If personalisation is to be successful, then people disabled and older people need access to high quality, impartial information and advice – with good knowledge of local services.

We would recommend the following:

- Ensuring that the family and carers of disabled people and older people (as well as those who need care) have access to clear information, advice and support services – via a national ‘offer’, setting out the information and advice they are entitled to.

- Increasing support for local advice and information services for people who need to access social care. This would help meet the Government's commitment to establishing at least one disabled people's organisation (DPO) in each locality by 2010.
- Ensuring that there is one funded independent advocacy organisation in every area; and creating a statutory right to an independent advocate for disabled people and older people who need support to make their own decisions.

## 2. The postcode lottery

Access to the current system of social care support is via an assessment of need. Though there are national 'Fair Access to Care' guidelines, these are interpreted differently by different local authorities, so entitlements and service provision vary significantly by postcode.

Additionally, pressure on resources has resulted in many local authorities tightening their eligibility criteria, so that fewer disabled people and older people qualify for services. In 2008, 73% of local authorities in England only provide services to those whose needs are assessed as being substantial or critical.

The variation in (and availability of) services creates significant inequalities both between and within local authority areas. This particularly disadvantages new claimants, who may have received services in the past, but are now judged ineligible.

The assessment process focuses largely on the risk to the individual if no support is provided. This tends to mean that assessments focus on people's physical needs, creating a 'feeding and washing' culture of support, rather than one which considers a person's needs – taking into consideration their emotional wellbeing and what they want to achieve with their lives.

**“I get support to get out of bed and wash but then I sit around in my flat all day because there's no-one to support me to go out. It's very frustrating and lonely.”**

A lack of clarity over who is responsible for funding social care services also creates problems for disabled people and older people who wish to move to another local authority area.

'Ordinary Residence' rules say that the local authority area in which a disabled person or older person is ordinarily resident, should fund their support. But the system is flawed and frequently leads to long legal disputes between local authorities over who should pay. These disputes often result in disabled people and older people experiencing significant delays in getting their social care needs met, or in some cases being prevented from moving area at all.

**“I took the big decision to move to London to take up a job offer... after [informing] my new local authority’s social services department many times of my arrival, my ‘care needs assessment’ occurred after my move date... the resulting report was left untouched for a further six weeks before going to panel where they approved three hours of care per day. It took a further six months of fighting before I got them to approve the 24 hour support I actually need.”**

For many disabled people and older people who wish to move out of residential care settings, or from a residential special school into a non-institutional setting, the 'Ordinary Residence' rules also create significant barriers.

Disputes typically arise when disabled people living in out-of-authority placements, wish to move out of residential care – but wish to stay living in the 'host' local authority area. Legal disputes regularly result in disabled people being unable to leave residential care. The Voluntary Organisations Disability Group estimates that at least 500 people are caught up in these 'Ordinary Residence' disputes at any one time, costing an estimated £3m a year in legal fees and administrative costs.<sup>1</sup>

**“I would like to move out [of residential accommodation]. My brother moved [into the] local [authority] years ago and now has a two bedroom place so I can live with him. But because I originally lived in another county [prior to living in residential accommodation] the authorities are debating over the funding. I do not know if or when I will be able to move.”**

### **Some suggested responses**

Provision of social care services is currently a lottery. Where someone lives, plays a major role in determining whether they are eligible for social care services. This is fundamentally unfair.

<sup>1</sup> <http://www.vodg.org.uk/?lid=3156>

To overcome this, we have a number of suggested responses:

- Investigate further the possibility of setting a national eligibility framework which is clearer and ensure more consistency within areas and across the country; so that people are sure that just because they move they would not be cut off from services that they had been eligible for in their home area.
- Easing the situation where if a person moves to another authority, the authority from which they come, remains responsible for funding (or providing the level of the personal budget) for a period of at least three months – whilst it is established whether the budget needs to be altered, depending on the costs of an equivalent package of care in the new area.
- Alternatively, consider researching the feasibility of separating the body that *funds* social care, from the body that *assesses* eligibility for services. Such a separation, would avoid eligibility being determined by the locally-available budget. This could include centralising funding for social care services, so that national eligibility criteria are applied consistently (wherever someone lives) and would avoid the barriers caused by the ‘Ordinary Residence’ rules. Local authorities would retain responsibility for supporting disabled people and older people through the assessment process and for strategic commissioning of locally-appropriate services (based on local population needs). Work would need to be undertaken as to how any allocation of resources to an individual would adequately reflect the geographical differences in the costs of purchasing care.

### 3. Choice and control

Having choice and control over where and how you live are fundamental to being able to live an independent life. However, many disabled people and older people have little control over basic decisions like when to get up, what to eat or whom to live with.

The majority of social care services are still designed and delivered in the way that is most convenient for the service provider, rather than the person using the service. This results in services that do not meet people’s individual needs or and do not support them to be independent and active citizens.

**“I would like support with cooking – I’d like to cook my own dinner and [have a] carer there to help me. At the moment she does it and tells me to sit down.”**



Disabled people and older people are too often not offered a choice of services and have to make do with what is available locally, even if it doesn't suit their needs or is of poor quality. Some disabled people and older people are denied services they are entitled to because they are not currently available.

**“I attend a day centre. No one ever asked if it was what I wanted. I was just told that this is the best place for me. I don't enjoy coming here.”**

Lack of choice and control also knocks the confidence and de-skills both disabled people and older people. Making decisions, maintaining friends and social networks and dealing with day-to-day events become harder. This often leads to isolation and depression – and can make people more dependent on others than they need to be.

**“I am elderly and live alone. I feel very isolated. I see no one for days and cannot go for walks because of the weather.”**

Direct payments and individual budgets have the potential to revolutionise social care. They put the service user in control, by giving them money in lieu of direct services. This enables disabled people and older people to buy the services and the support they choose and to determine how they are provided.

Despite their popularity, take-up of direct payments is still very low. Only 32,000 individuals and families used direct payments in England and Wales in 2006 – 7 and only 10,200 were used by older people.<sup>2</sup>

Though take-up is growing, people are still finding it difficult to get direct payments and there is often a lack of support and information on how to use direct payments effectively.

**“My son was never offered direct payments. We learnt about direct payments from Scope and they have changed his life for the better.”**

People living in residential or nursing homes are not able to use direct payments. Under current rules, people living in residential care, whose care is paid for by the local authority, can only keep a Personal Expenses Allowance of £21.15 a week.<sup>3</sup> This effectively denies people any level of financial independence.

<sup>2</sup> [http://www.csci.org.uk/PDF/20080128\\_SOSC\\_2006\\_07\\_Appendices.pdf](http://www.csci.org.uk/PDF/20080128_SOSC_2006_07_Appendices.pdf)

<sup>3</sup> <http://www.disabilityalliance.org/f4.htm>



Both choice and control for disabled people and older people are further compromised because continuing health care budgets cannot be incorporated into direct payments.

Being able to exercise greater choice over the type of care they receive can make a big difference to someone's quality of life. However, at present, health and social care systems do not work together for the benefit of the user.

### **Some suggested responses**

Without choice and control, disabled people and older people cannot enjoy equal citizenship and are at a greatly increased risk of institutionalisation within their own homes or in residential settings. To tackle this, we would recommend the following actions:

- Consider creating a set of guaranteed minimum outcomes that all disabled people and older people will be supported to achieve and ensure people are clear about the amount of funding they are entitled to for their support.
- The Care Quality Commission could be charged with inspecting registered social care providers against a set of quality standards which measure the extent to which a service supports independence, choice and control for the user. The results of these inspections should be publicly available, so that users can make informed choices about the services they purchase.
- Consider creating an outcome-based assessment process that identifies the support an individual needs to achieve their own personalised outcomes. This would help move away from the 'washing and feeding' culture – to one which recognises social care as a tool that enables disabled people and older people to exercise choice, control and independence over their day-to-day lives and their future.
- As suggested in the latest welfare reform Green Paper, consider creating a statutory right to control your own support, to give all disabled people and older people a clear legal right to individual budgets, so that they can determine where and how they live. Ensure this is available to all disabled people and older people, including those who live in residential institutions.
- Consider funding direct payments and individual budgets, by pooling resources from the widest possible set of existing funding streams – so that people can exercise maximum control over the funds available to them.

- Investigate further the possibility of placing a duty on local authorities (similar to the duty to ensure adequate provision of child care services) to ensure that social care service provision in the local area is sufficient to guarantee that all recipients of individual budgets (or direct payments) have a choice of services that meet their needs.

#### 4. Paying for social care

At present, social care services are means-tested. Disabled people and older people who are eligible for state support are means-tested. Local authorities have the power to charge individuals for the social care services they provide.

Charging policies vary considerably across the country and it is common for people to pay different rates for identical services, depending on where they live. In 2006 – 7, disabled people and older people paid £2 billion pounds in social care charges.<sup>4</sup>

Disabled people are already more likely to have fewer qualifications and are less likely to have a job.<sup>5</sup> Both disabled people and older people are much more likely to live in poverty.<sup>6 and 7</sup>

For those on modest incomes, charging for vital services simply exacerbates these disadvantages. Increasingly, disabled people and older people report having to choose between basic things like eating or having the heating on <sup>8</sup>, because they can't afford both.

**“I have cut back on laundry and housework, but cannot do without personal care and help with meals... I very rarely buy new clothes or shoes.”<sup>9</sup>**

Inadequate or unaffordable social care impacts on people's ability to work, gain new skills and participate in community life – creating dependency, isolation and wasting people's potential.

Poor quality or inadequate social care can have a direct impact on people's health, and their ability to manage their condition effectively – making them more likely to need access to other services; often crisis, health and mental health services.

<sup>4</sup> [http://www.csci.org.uk/PDF/20080128\\_SOSC\\_2006\\_07\\_Appendices.pdf](http://www.csci.org.uk/PDF/20080128_SOSC_2006_07_Appendices.pdf)

<sup>5</sup> <http://smf.co.uk/assets/files/publications/Disability,%20skills%20and%20work.pdf>

<sup>6</sup> [http://www.ageconcern.org.uk/AgeConcern/Documents/Just\\_above\\_the\\_breadline\\_report\\_2006.pdf](http://www.ageconcern.org.uk/AgeConcern/Documents/Just_above_the_breadline_report_2006.pdf)

<sup>7</sup> <http://smf.co.uk/assets/files/publications/Disability,%20skills%20and%20work.pdf>

<sup>8</sup> [http://archive.disabilitynow.org.uk/search/z07\\_08\\_Au/bigpoverty.shtml](http://archive.disabilitynow.org.uk/search/z07_08_Au/bigpoverty.shtml)

<sup>9</sup> Charging into Poverty? Charges for care services at home and the national debate on care reform in England (2008), Coalition on Charging, London

Most disabled people and older people have told us that the current system of charging for social care services – which often delivers poor quality and inconsistent services – is unfair.

This is confirmed by further consultations that Scope (and other disability organisations) had with disabled people, where the majority of disabled people think that charging for social care services is unfair.

The opinion amongst older people has been more mixed, with some suggesting that co-payment for care services (with a care guarantee paid for by the state) would be acceptable.

Whatever funding model emerges, an increase in public funding will form the core of a new settlement and that money must be used to improve quality and ensure that those who cannot afford to pay for their own care, receive adequate services.

**“Why should we have to pay to get out of bed and have a shower? No one else has to pay for this.”**

The Government has acknowledged that the social care system is in need of urgent reform. It has also said that funding social care through general taxation is not a realistic option.

However, for the many disabled people who have never had an alternative to a lifetime on benefits, paying for their care is simply not an option.

The number of older people and disabled people is increasing, as is demand for social care services. Unless we develop a fair and sustainable system for paying for social care, more and more disabled people and older people will become reliant on informal carers for much of their support.

Over five million people provide informal care to a disabled person or an older person.<sup>10</sup> Many informal carers are unable to work because their caring responsibilities make it impossible.<sup>11</sup>

Carers UK estimate one-in-three carers are not able to return to work because the right alternative care is not available. One-in-five carers are forced to give up work because of their caring responsibilities and many are discriminated against in the workplace.<sup>12</sup>

<sup>10</sup> <http://www.statistics.gov.uk/cci/nugget.asp?id=347>

<sup>11</sup> Carer's Allowance (paid to those who provide a minimum of 35 hours care a week, equivalent to a full-time job) equates to a maximum of £1.44 per hour – well below the minimum wage. As a result, informal carers are more likely to live in poverty and much less likely to be paying national insurance or saving towards a pension.

<sup>12</sup> <http://www.carersuk.org/Newsandcampaigns/makeWORKwork>

**“My mum and dad already have to do too much for me... But I don’t have any choice and nor do they. If I stopped having services they would have to do more... I am too reliant on my family already for support... I used to get services about 12 to 14 years ago and things were good then. I got what I needed and I didn’t have to pay. Now things have changed and it’s made my life and my family’s life much worse.”<sup>13</sup>**

### **Suggested responses**

How to fund social care is one of the most important political debates of this generation. The wrong solution could plunge hundreds of thousands of disabled people and older people into poverty and further widen the gap between rich and poor. As our population ages, social care will increasingly become an issue for everyone, as working age people are called upon to support their parents.

- The NHS should consider investing much more heavily in preventative services, high-tech equipment, therapies and condition management support – so that disabled people and older people can maintain their independence for as long as possible.
- Consider reducing the red tape and duplication within the current social care system, to free up more money to spend on direct services. A single assessment of someone’s needs and pooling of all income streams, would help reduce inefficiencies, as well as improve the experience of the person being assessed.
- Undertake economic modelling to estimate the costs of different options for funding social care. The findings of this study should be contrasted with the cost to the state, if care is funded by individuals. This should focus (in particular) on the numbers of people living in poverty, impact on tax revenues, employment rates, use of acute health services and the ability of disabled people and informal carers to save for their older age.

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<sup>13</sup> Charging into Poverty? Charges for care services at home and the national debate on care reform in England (2008), Coalition on Charging, London.