

a constitution
for social care
accompanying
report

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All errors and omissions are our own.

Jamie Bartlett & Silvia Guglielmi
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1 introduction

What is social care?

Social care is an essential public service, which supports disabled people, people with impairments, and older people who need help to maintain their independence and have full and active lives. The level of care varies from the full-time assistance needed by someone with a complex physical or learning disability to providing help to an older or disabled person with daily activities like washing or cleaning. In 2009 over 1.75 million people are supported by some level of state funded social care provision.¹ The Wanless Review suggested that there are two main aims in providing social care:

*first, ensuring that people are able to live in safety and to satisfy personal care needs, including feeding, washing, dressing and going to the bathroom; second, enhancing well-being and social inclusion.*²

The distinction between health and social care provision is a complex one, and is generally related not to the condition a person has, but to what need they have. Where NHS provision is anything 'health related', social care services cover a wide range of 'caring' services:

- disability equipment and adaptations in the home
- day centres to give the person or the carer a break
- day care
- care homes
- domiciliary care and home-based services

Social care services are administered and delivered by local authorities. Unlike the NHS, social care services are not free at the point of delivery, but are means tested. If an individual has eligible assets of more than £21,500 he or she normally gets no local authority support.³ Therefore approximately half of all older people using social care services (figures are not available for other groups) pay for their own care out of their own pocket.⁴

Social care is also 'needs' tested. Everyone who enters the social care system is assessed by a trained social worker, and this assessment determines whether that person qualifies for publicly funded support, according to whether their needs are critical, substantial, moderate or low. These categories are determined by reference to a national eligibility framework known as Fair Access to Care Services (FACS). Local authorities decide which categories of people should be eligible for publicly funded support.

The crisis facing social care

There are four interrelated challenges that are facing social care:

- demographic changes
- unfairness
- the postcode lottery
- complexity and incoherence

Demographic changes

Provision of social care has reached a critical stage. The twenty-first century will witness huge demographic and societal changes – with an ageing population and growing complexity of needs. In the next 20 years the number of people aged 85 and over in England is set to increase by two-thirds and the number of people aged 50 and over with learning disabilities is projected to rise by 53 per cent between 2001 and 2021. Overall, the number of people who are impaired or dependent will increase significantly over the next 20 years. This means that demand for support across the continuum of need will increase.

At the same time, unit costs of providing care are increasing.⁵ The number of national minimum standards met by social care services has risen in the last five consecutive years, according to the Commission for Social Care Inspection (CSCI), but the rate of improvement is slow and indicators are still being missed.⁶

Unfairness

Concerns have been raised about the unfairness of the way social care services work. Because it is means tested, people with sometimes very limited savings and assets must often contribute substantially to the cost of their own care, driving them to the edge of poverty. Recent work has suggested that those people who pay for their own care can be highly vulnerable, isolated and at risk of being 'fast-tracked' into residential care, equipped with little information or advice to use in making life changing decisions.⁷ Means testing in social care has always been controversial as it raises issues of fairness about 'penalising' people (mainly older people) who have saved up money, which they then have to spend on care which others get for free.

Partly because of tightening budgets, social care is heavily rationed. It is increasingly only those with the most critical needs and fewest personal resources who are eligible to receive publicly funded help. As a result there is an increasingly sharp divide forming between those who qualify for and benefit from the publicly funded social care system and those who are left outside it. In 2006/07 two-thirds of local authorities provided social care only to those deemed to have 'substantial' or 'critical' needs; by 2007/08 almost three-quarters of local authorities were operating at this level. This leaves hundreds of thousands without the support they need.

In 2006/07 CSCI estimated that 6,000 older people with high support needs and 275,000 with less intensive needs received no services and had no informal care. Leonard Cheshire Disability's 'Disability Review 2008' is based on the findings of a survey of more than 1,000 disabled people. It found that the number of disabled people receiving publicly funded social care services is beginning to decline. The survey found the most substantial drop was among those people who had lower levels of need, but there was also a drop in the number of people with low incomes receiving care services. The impact of this increasing gap in social care

provision can be dramatic – with people being forced to rely on family and friends, including young children, to provide some informal care support, or being forced to make impossible financial choices, for example between paying for social care or heating a home.⁸

Reaching this group will be a key part of the desired shift towards preventative services within social care. Over half (52 per cent) of the respondents to Leonard Cheshire Disability's report *Your Money or Your Life* report stated that the shortfall in social care services had led to more accidents, serious illness, suicide attempts and/or visits to the doctor and hospital.⁹ Around 14 per cent of respondents were very concerned that it had also led to illness, accidents and stress in their carers.

One of the consequences of means and needs testing has been a huge expansion of an extensive hidden economy, which is rarely considered alongside public expenditure. Those who fall beyond current eligibility requirements often obtain support from friends and family members who act as carers, and the vast majority are unpaid. CSCI found in 2005/06 that only 383,000 informal carers received an assessment for their support needs, and 142,000 received a service, yet there are an estimated 6 million carers in the UK.¹⁰ It is estimated that there are six times as many people providing support to family and friends for free as there are people being paid to do so – the value of the work done by unpaid carers is estimated to be around £87 billion a year. People who decide to become unpaid carers often have to sacrifice their own well-being, and endure considerable financial and personal hardship. A recent survey by Carers UK found that 65 per cent of carers are living in fuel poverty; half are cutting back on food to make ends meet; and a third can't afford to pay their mortgage.¹¹

The postcode lottery

The 'needs testing' has also led to a serious postcode lottery. Unlike other postcode lotteries, it is not an issue of service quality. Where you live can make the difference between your receiving the help you need to live your daily life, and receiving no support whatsoever.

This postcode lottery means that those with similar needs for support are treated wholly differently in different parts of the country. Social care, in fact, suffers

from a number of different postcode lotteries: the differing application of FACS, resulting in differential access to support and the lack of 'portability' of assessments; a big range in the charges levied for non-residential services; and wide variations in the support offered to carers and in the provision of open access services. This results in confusion and dissatisfaction among service users and carers, who do not understand how the system could be considered fair.¹²

Complexity and incoherence

Finally, the current social care system is extremely complicated and often incoherent. As we discovered, very few people who use social care services can confidently claim to understand how the system works, and what they are eligible for. The legal framework for adult social care is widely recognised as inadequate, incomprehensible and outdated. It remains a confusing patchwork of often-conflicting statutes enacted over 60 years. There is no single, modern statute that underpins the key values and principles of adult social care for service users, carers and social care staff to consult to find out whether services can or should be provided and, if so, what kinds of services. Adult social care legislation still reflects the philosophical, political and socio-economic concern of the post-war Labour government.¹³

Worryingly, the recent review of FACS by CSCI found that the people who don't meet current eligibility thresholds are often not given any information about what other help might be available.¹⁴ Indeed, the infrastructure around long-term conditions and social care exemplifies the limit of public services to meet people's holistic needs. Services and funding are provided through a tangle of budgetary streams, each with different forms of accountability and rules (Table 1).

Table 1 **Budgetary streams for social care**

Funding stream	Amount	Administered by	Covering
Disability benefits (incl. disability living allowance, attendance allowance and incapacity benefits)	£22 billion	DWP via Jobcentre Plus or Pension, Disability and Carers Service	Those unable to work, in need of care or facing additional costs due to disability
Adult and children's social care	£20 billion	Local councils	More than 1 million users at any one time
Supporting People programme	£1.6 billion	Local councils and related organisations	Those with learning, sensory or physical disabilities
NHS core funding (incl. NHS Continuing Care and NHS Funded Nursing Care)	£20 billion	NHS via PCT or nursing home	Those living with long-term health conditions
Independent Living Fund	£0.34 billion	Independent Living Funds (a non-departmental funding body)	Direct payments for disabled people who meet strict eligibility criteria
Disabled Facilities Grant	£0.12 billion	Local councils	Facility adaptations in disabled people's homes

The system lacks clarity and transparency in practice due to the complexity of the framework, so neither professionals nor people using services are confident of their understanding.¹⁵

Why now

The system as it stands is unsustainable. But social care does not enjoy the same recognition as other major public services, even though most of us will need to use social care services at one point in our lives.

If William Beveridge were designing a welfare system today, he would put social care provision at its heart. *When he wrote the founding document of today's welfare state, Social Insurance and Allied Services, in 1942, he famously set out how to overcome the five 'giant evils' of the day: want, disease, ignorance, squalor and idleness.¹⁶ Today, an evil as great as any of these is lack of care.*

This is why we have decided to produce a social care constitution. The general recognition that social care is underfunded and unsustainable has led to the government signalling a willingness to find a new settlement for social care. In 2009 the Department of Health will produce a green paper on the future of social care funding. Partly as a result of concerns about eligibility, in early 2008 the Department of Health ordered CSCI to review FACS, mentioning 'unintended consequences' of letting councils set their own rules based on FACS. In addition, the Law Commission is currently reviewing the state of social care legislation with a view to creating a simpler, single statute for how social care works. This is an excellent opportunity to build a better system.

2 our research

Rationale

The debate on social care funding has tended to concentrate on the needs of older people and there is a danger that younger disabled people's concerns could be under-represented. For this reason, we decided to focus on disabled people of working age for the purposes of this research. Drawing on the recently published NHS Constitution¹⁷ we decided that as the debate on the future of social care moves forward, setting out a constitution for social care would offer a powerful vision for how social care should look. We structured the constitution itself around the following themes:

- principles that guide social care
- what social care pledges to you
- your responsibilities to social care
- social care pledges to carers and families
- social care staff pledges to you

Methodology

Our research was carried out with Leonard Cheshire Disability and the Multiple Sclerosis Society (MS Society). It centred on five workshops, which gathered together 55 disabled people and their carers. The workshops took place in York, London, Leamington Spa, Surrey and West Sussex, between July and September 2008. Participants were invited through open advertisements via local authorities and through Leonard Cheshire Disability and MS Society branches.

Participants in the workshops reflected a wide range of needs, impairments and ages, and included both self-funders – people who pay for their own care – and people whose social care services are paid for by their local authority. Some participants were accompanied by their carers.

Workshops were a good mixture of ‘activists’, people involved in policy making with a deep knowledge of social care issues and how the system works, and other individuals who had less knowledge or experience of the complexities of the system. The most numerous group was people with physical disabilities – notably multiple sclerosis. However, there was a wide variety of conditions and life stories of the individuals that attended.

We asked participants to consider an array of themes through innovative and open sessions. We supplemented this qualitative work with structured questionnaires and in-depth seminars with two local authorities to work through the practical implications of our findings. The workshops were divided into three main sections: rotating tables, learning journeys and questionnaires.

Rotating tables

In order to make up the substantive content of the constitution itself, we asked participants to answer the following questions:

- What should social care be aiming to achieve?
- What do you need from social care services?
- What are your responsibilities towards the care system?
- How should staff/personal assistants treat you?
- What support should carers get?
- Who should be eligible for free social care, and what should they expect?

The exact responses are shown in the tables below.¹⁸ Participants felt that the overriding point of social care is to help people realise equality with non-disabled people, and improve their quality of life. Related to this was the importance of them being able to live independently and with dignity.

What should social care be aiming to achieve?

- 30%** Improving quality of life, realising equality with abled-bodied people and [helping] people be happy
- 16%** Enabling independent living for social care users and helping give independence and dignity
- 10%** More information with emphasis on what is available in terms of provision from GPs, consultants, private NHS etc...'
- 8%** Integrated care services and a holistic approach

To help achieve this, participants stressed the importance of having personalised services that respond to the whole life circumstances of the person, and not just their disability or impairment. They thought it vital that local authorities should work in a simple, quick and efficient way – people raised a number of concerns about seemingly quite simple problems such as returning phone calls quickly.

What do you need from social care services?

- 18%** Different needs to be recognised as different, even within the same conditions; a more fine grained assessment process
- 16%** Speedy assessment and speedy realisation of care provision, especially as it is often needed urgently
- 16%** An easy place to go for support, advice and guidance that is prompt and returns calls
- 14%** A system that is easy to understand and use
- 10%** Flexibility of what is provided when needs change in the short term

All participants recognised the importance that social care services are in some senses a deal – that they also have responsibilities to helping make the system function as

cheaply and as effectively as possible. Participants considered it most important to be honest about one's needs, as there were some concerns that people are able to 'cheat' the system, making it worse for everyone. However, other participants noted that in some cases people are forced to exaggerate their difficulties in order to access the support they need.

What are your responsibilities towards the care system?

- 23%** Not to abuse the system and always be honest on my needs – not claim what I don't truly need
- 23%** Treating carers with respect
- 16%** Sharing information, keeping staff updated on my needs and giving feedback
- 14%** Saving the state as much money as possible, and not wasting state funds

There was a general recognition of the importance of staff and personal assistants, and of the importance of the personal relationship. There was also a general agreement that the range of quality of staff varies greatly. Most striking was the sense that power should rest with the service user, who should be recognised as a person, not simply a problem or a disability.

How should staff/personal assistants treat you?

- 28%** As a person, not as a disability.
- 26%** As though the user is the paying customer, or as the expert on their own condition: that they are in charge.
- 18%** With respect.
- 18%** Staff and personal assistants should be more informed and knowledgeable
- 10%** Guaranteed continuity between staff – and better time keeping

As other research indicates, there was a widespread acceptance that carers do not receive sufficient support, in particular financial and respite support.

What support should carers get?

- 25%** A proper salary or a decent wage for caring
- 19%** More respite cover and have a decent break from caring
- 14%** More information on the help available
- 10%** More training and ongoing professional training and support

Overwhelmingly, there was support for the idea that social care should be free for everyone who needs it; and concerns were raised about the injustice of what feels like a 'disability' tax on those who require support. However, a number of participants also recognised that if people could afford to pay for their own support, they should be expected to contribute something, as this improves the system for everyone as it would bring additional resources into the system as a whole and ease the financial strain.

Who should be eligible for free social care?

- 65%** Everyone, no matter what their wealth
- 21%** Those who can't afford to pay for it themselves
- 9%** Everyone should receive a set amount of provision, which is then topped up so everyone gets something
- 6%** Those with needs greater than a specified level

What should people receiving support expect?

- 25%** Provision of electric wheelchairs for those who need them
- 25%** Whatever they need to retain their quality of life
- 13%** Good transport connections, with improved access
- 13%** Dignity
- 13%** Honesty
- 13%** Clear information

Learning journeys

Learning journeys allow people to use a combination of pictures and keywords to make a strong contribution to the debate over the future of social care. Learning journeys are also called 'rich pictures' and are associated with systems thinking. The idea is that using pictures to illustrate challenges helps to explore interconnectedness and forces people to adopt a slightly different perspective and way of thinking about issues.¹⁹ The process enables people to describe their personal experiences of obstacles and consider solutions to problems.

Participants must illustrate what hurdles they face in reaching a final destination and how they overcome them. The following three objectives were set:

- **Objective 1:** A social care system that offers choice and gives each individual the type of support that they want
- **Objective 2:** A social care system which is easy to understand and use
- **Objective 3:** A social care system that is affordable both for the individual and for the state

Objective 1: A social care system that offers choice and gives each individual the type of support that they want

There was a general recognition that, along with other problems, part of the difficulty of achieving this objective is a financial one: the size of the total social care budget is too small, and within that budget, too much money is spent on bureaucracy and form-filling. More specifically, a common concern about a lack of choice was the general incoherence of the system, in particular when people are at the ‘point of entry’ – when they first apply to the system. A number of participants recalled how confusing it was at that stage and how little they knew what to expect.

To overcome these barriers, many respondents suggested that people should have access to clear, accessible information at the start about what you could expect and how to go about getting it – including through a one-to-one adviser, whether local authority staff or a peer who already knew the system. A number of groups highlighted the positive roles that user groups can play, including service providers who are often very knowledgeable about the infrastructure of social and health care in a local area.

The most common barriers to achieving this objective were that:

- service users don't know exactly what they are entitled to at point of entry
- there is too much bureaucracy and form filling – makes it more confusing
- staff lack appropriate skills and courtesy to help assist choice
- social care doesn't give enough flexibility and options for the type of support that disabled people can receive

The most common ways to overcome these barriers were:

- to provide clear, accessible information at the start about what you are entitled to, how you can get it
- to use the National Council for Independent Living and e-learning professional development more for public deliberation, and places where disabled people can advocate for their rights
- to have more dedicated user groups to offer peer-to-peer support for people who need it
- to have one member of staff who can advise on options that are available

Objective 2: A social care system which is easy to understand and use

Similarly to objective 1, the problem of bureaucracy and form-filling was considered to be the most important barrier to creating a social care system that is easy to use. A number of participants complained that form-filling was time consuming, difficult and often demeaning. One participant stressed that it was particularly frustrating to fill forms out annually when nothing had changed in her condition. Interestingly, there was a general sense that one

of the reasons social care is sometimes confusing is that there is too much information available – and it is hard to know where to go for it. Very few participants knew anything about the reform of social care, and the introduction of personal budgets, and felt that there was still too little flexibility in the system, especially in the assessment process. However, it is important to note that a number of participants pointed out that they were content with the services they receive and would not like them to change.

Participants overwhelmingly felt that it would help to make the system simpler and easier to understand if they had personal contact with people in the local authority. One participant wanted someone from the local authority to fill her forms out for her. Several participants suggested that this difficulty could be overcome by creating dedicated advisers who know about all aspects of social and health care and can provide in-depth, face-to-face support. This person would become a named point of contact.

Most participants would prefer to fill in a single form rather than multiple forms when they are assessed. Two groups argued for a single database, which would cover social and healthcare records, but other participants did not agree, saying that they preferred that social care workers didn't know everything they had spoken to their GP about, for example.

The most common barriers to achieving this objective were that:

- there is too much bureaucracy and form filling – makes it more confusing
- there is too much information, not too little; participants disliked constantly being bombarded with irrelevant things, which is confusing
- support is still too top down in terms of what services you get
- people are boxed in to certain categories; there is not enough flexibility in the assessment process to make fine distinctions

The most common ways to overcome these barriers were:

- to have dedicated advisers who know about all aspects of social and health care and are able to provide the in-depth face-to-face support that is needed
- to have one place where people can go for advice and guidance
- to have only one form to complete
- to have one centralised database

Objective 3: A social care system that is affordable both for the individual and for the state

All participants recognised that social care is underfunded, but that it is not possible for social care to have unlimited resources. However, there was a sense that on balance it is generally undervalued as a service compared with other major public services like the NHS.

Participants explored a range of possible solutions to these barriers. One group focused on the importance of changing the system of testing means and needs, arguing that too many people are currently excluded from publicly funded social care, which means that the government's plans for reforming social care by introducing personal budgets will not affect all those people currently excluded. One participant suggested that local authorities should consider increasing social care support staff by recruiting minor offenders to help people with some of their daily activities, bringing benefits to both parties.

Although there was recognition that social care was just one aspect of many public services, there was also a sense that it was generally underfunded because of a lack of awareness among the general public about what social care was for, and so there is a need to raise the profile of social care. A common suggestion to save money was to make greater use of the skills of service users themselves: they could offer training courses for staff, sit on local authority panels, and help to provide advocacy services.

This was considered positive because it would result in a better service, engage more service users, and also cut costs.

The most common barriers to achieving this objective were that:

- there is too much bureaucracy and form filling – this is unnecessary waste
- the means testing system is unfair
- this issue is not prioritised nationally – the size of the cake is too small
- there is a lack of awareness about where the money is spent

The most common ways to overcome these barriers were:

- to involve disabled people in all forms of decision making can save huge amounts of money
- to change the system of means testing; the threshold is too high and eligibility too strict
- to create greater awareness at a national level about the social care system, which should translate into greater willingness to invest more
- to make more information available to users about how much things costs

Questionnaires

All participants filled out questionnaires in order to generate quantitative data, which complemented the qualitative information gathered throughout the day. The questionnaires also provided an opportunity for participants to voice their opinions in confidence. These were closed, multiple-choice questionnaires.

Figure 1 'Do you think it would be useful to have a set of underlying principles for the social care system, to set out who is entitled to what?'

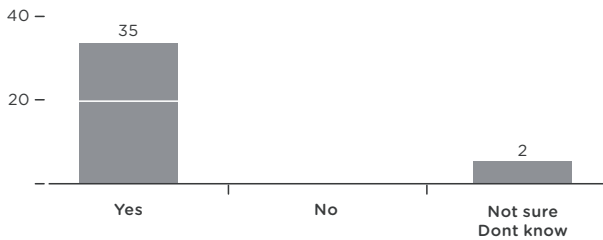


Figure 2 Participants who agreed or disagreed with the following statements

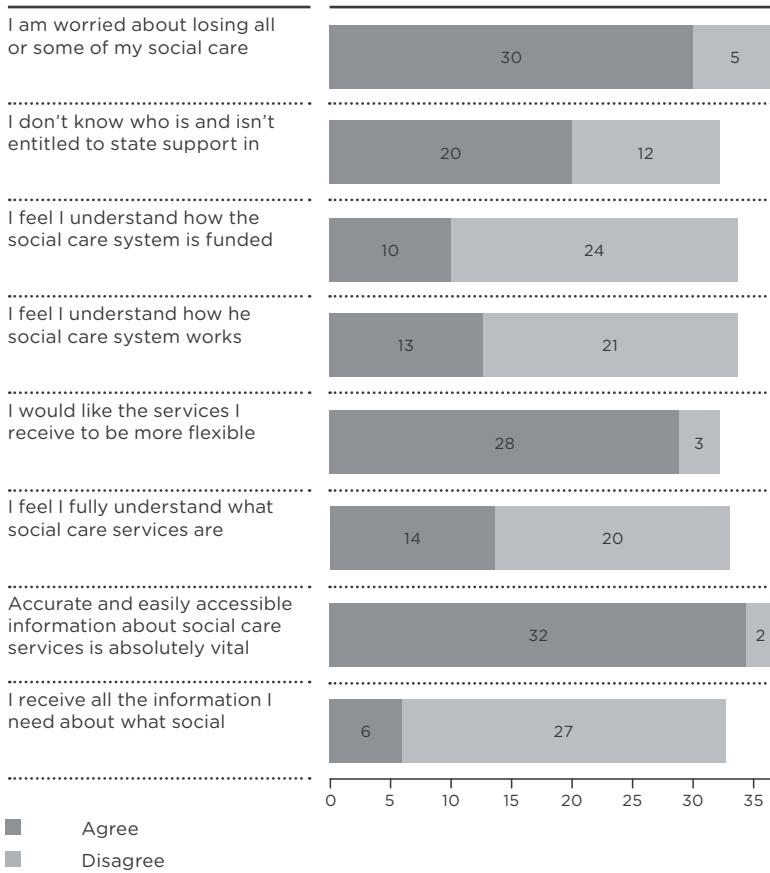


Figure 3 Do you think the government should reform the way people pay for social care?'

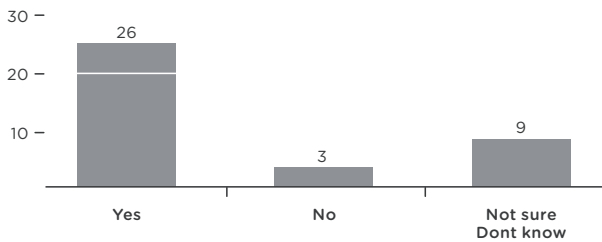


Figure 3 **If yes, do you think that one of the options below would particularly make the system better?**

- 36% There should be a basic minimum level of care offered free by the state, but individuals can 'top-up' by paying extra themselves
- 26% I think that the current funding system is fine, but some changes to the criteria are needed
- 19% The state should provide free social care to anyone who needs it, regardless of their incomes
- 14% People who can afford it should pay a lump sum of money into an independent national care fund, but if they choose not to pay then they will have to pay for their own social care
- 5% None of the above

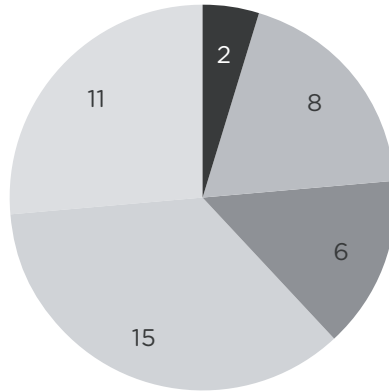
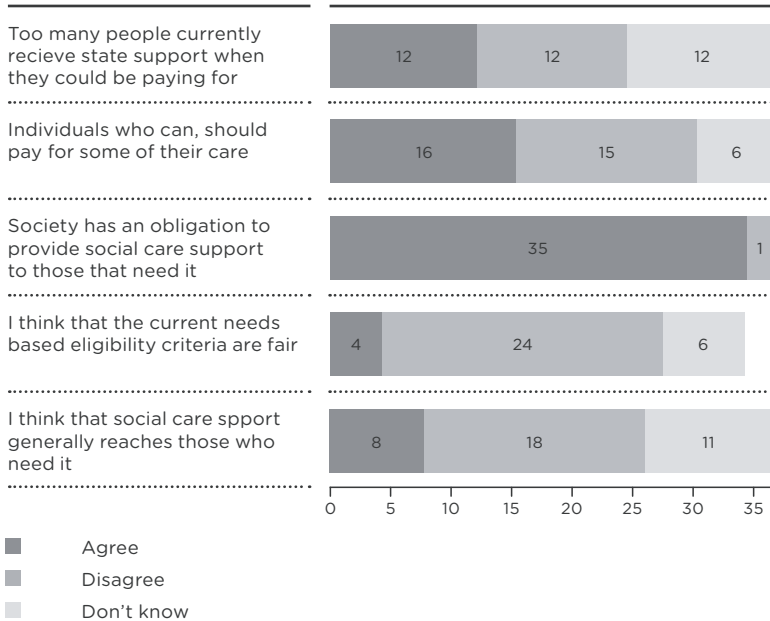


Figure 4 **Participants who agreed or disagreed with the following statements**



The MS Society also supplemented our questionnaires with an additional one. A random sample of MS Society members, half of whom were under 45 and the other half over 45, filled in 1,089 questionnaires; 635 were completed by people with multiple sclerosis and 454 by carers. The key findings to emerge from this survey were that:

- 11% strongly agree that they understand which care services would be entitled to
- 88% strongly agree that people should be entitled to the same services irrespective of where they live
- 67% strongly disagree that people with a home or savings should use this money to pay for care
- 66% strongly agree that everyone should be guaranteed services regardless of wealth

The full responses to this questionnaire can be found in the annex.

Local authority sessions

Immediately following the five workshops, Demos met representatives from two local authorities to present and discuss the findings, and consider how practical they were. This assured a smooth and useful process by which service users' voices were heard by the local authority, yet no false promises were made to them.

Summary of key findings

The findings from the five workshops fed directly into the constitution and formed the backbone of the entire research process. The key issues that emerged are discussed below.

Part 1: Principles that guide social care

Social care should be about realising equality with non-disabled people. Respondents considered that the most important function of social care was to help improve the quality of people's lives, and to help them achieve equity with non-disabled people. Participants wanted more control over what they received, and recognition that they are individuals. Even where people have the same condition, their needs and life circumstances are very different.

Eligibility to some services for all. The overwhelming view of workshop participants was that social care of some sort should be available to everyone, regardless of their ability to pay. Ideally this means making social care a genuine public service, freely available to all who need it, like education or health provision.

There should be some contribution from individuals. In line with other research described above, workshop participants recognised that although there is little political will to fund such a service, it was important to consider the nature of individual contributions from those who have the means. Over 50 per cent felt that the best way to reform the funding system would be to rely on a basic level of care provided free by the state to those who need it, with individuals topping up that minimum package by paying extra themselves. Although a specific definition of 'a basic minimum level of care' was not given, it was assumed by participants that this would not simply be an information service, but an agreement from the government to provide the basic social care support that an individual would need.

Widen the eligibility thresholds. Our research on the issue of eligibility found that people are frustrated and want the eligibility threshold to encompass more disabled people. Participants generally thought that means testing was more reasonable than needs testing but nonetheless could be improved. The differences between local authority monies available means that services are infinitely worse in some parts of the country than others. If free social care is not an immediate option, most people are prepared to pay something for care, if they can afford to do so, but want this to be within a transparent and effective system. There is often some disparity between the views of older people and disabled people of working age about funding for social care, with younger disabled adults more likely to feel that social care should be a free public service, and older people more

willing to contribute to the costs of care. In part this is likely to stem from the fact that younger disabled adults will use social care throughout their life, and are far less likely to have had the opportunity to build up assets to pay for social care support.

Part 2: What social care pledges to you

People are still unclear about what they can expect from social care services. People who use social care services find the system extremely confusing and complicated.

The questionnaires revealed that 63 per cent of disabled people of working age don't know who is and isn't entitled to state support; 71 per cent don't understand how the system is funded; and 62 per cent don't know how the service works. More worryingly, 82 per cent do not receive all the information they need about what social care services are available to them. The following quote from a workshop, for example, highlights this problem:

We need clear information in easy language – everyday language, to explain the system and what we're entitled to. If you don't know the technical words you will never navigate the system, and if you don't show that you know that language no one will help you.

Anonymous

This supports CSCI's review of FACS, which found that lack of information was particularly acute among people who do not meet current eligibility criteria: 62 per cent of survey respondents who did not meet eligibility thresholds stated they were not given any information about other help that might be available. Without the necessary information it will be impossible for disabled people to exercise full independence, choice and control in their lives.²⁰

Social care services are still too slow to respond. The provision of timely and appropriate social care support is vital to many disabled people's independence. When asked to prioritise what they needed from the social care system, 16 per cent of participants in our workshops said that their first priority was to have speedy assessment and speedy realisation of care provision, especially as it is often urgently needed. However, the process of receiving care was felt to be too time-consuming and wasteful. The most common complaint from users was that too many forms made the assessment process extremely time-consuming and detrimental to people's well-being, and slowed the system

down dramatically. If the system is to meet social care users' needs in a timely and appropriate fashion, the assessment process must be streamlined and designed in such a way that it does not place an undue burden on those who need the support. As one respondent told us:

Our greatest difficulty is in getting a swift and coordinated response to our needs. A visit by the NHS occupational therapist may identify urgent needs but paperwork and involvement of social services seriously delays the response [so] by the time we get action, we need something further. We are always playing catch up.

Claire, workshop participant

There is not enough flexibility to respond to short-term changes in people's conditions. People's situations and impairments can change dramatically in a short space of time (for example their impairment might fluctuate or their informal caring arrangements might unexpectedly change), yet the support provided by the social care system is often not flexible enough to meet these changes in circumstances. In our workshops, 10 per cent stated that providing greater flexibility to make short-term alterations when an individual's needs change was their priority for reform of the social care system. This is especially true of people with fluctuating conditions like multiple sclerosis, for whom sudden changes in their condition often result in considerable hardship for the individual and extra burdens on families and informal carers. In the MS Society survey:

- 95 per cent of people with multiple sclerosis said that better services during a relapse or sudden deterioration of their condition would help them maintain their independence
- 91 per cent of carers said that they were the main giver of care and support during a relapse or sudden deterioration of their friend or family member's condition
- 91 per cent of carers believed that having access to services during a relapse or sudden deterioration of their friend or family member's condition would help them balance caring with other aspects of their life

People want clearer – not always more – information about what they can and can't expect from social care and this needs to be clear and easy to locate. The creation of personal advisers was considered to be a good way to achieve that. As one participant put it:

They [staff] don't listen, they think they know what you need. They send out a lot of info and they don't send us the info that we need. [Users must] be careful about demanding more information, or the right information. We need clear language and clear structures too.

Glynis, workshop participant

Reduce administration costs. This could be done partly by involving disabled people more in decision making, and partly by reducing the amount of form filling that is required.

Part 3: Your responsibilities to social care

Recognising our own responsibilities. Our sample group recognised a broader set of responsibilities that social care users have to the social care system as a whole. People overwhelmingly felt that they had a set of responsibilities to the social care system: to be well informed, honest and transparent about issues and problems that are being experienced. Indeed, one of the most persistent concerns raised was that people have to 'exaggerate' their impairment in order to access public money.

Financial contributions. Most respondents felt that people who can afford to should contribute financially to their own social care, provided that their contributions are spent transparently. It is clear that there is potentially a role for individual contributions in the social care system: the Local Government Association recently commissioned a survey of 16–75 year olds, which looked at the willingness of people to make a bigger contribution, and nearly three in five people would be willing to match what the council pays for care. Caring Choices also carried out some research, which showed that just under three-quarters of all participants believed that the costs of long-term care should be shared between the government and the individual.²¹ All of these assume an individual's ability to pay.

Disability tax. At the same time, however, it is important to remember that many disabled people consider being means tested and charged for social care services amounts to a ‘tax’ on their disability. This was a common view stemming from the workshops:

I already pay council tax. It's the same for the police service. I pay tax which pays the police officers, bureaus and community officers. If I get burgled and the police come to my house, I don't pay them extra – they don't charge me for that. So why should I pay for my social care? It's an extra tax, because I'm disabled.

Sanjay, workshop participant

It is vital that financial circumstances are acknowledged vis-à-vis the time-frame of a disability. For many adults with lifelong impairments, building up assets, such as substantial capital holdings, is extremely difficult. Disabled people are twice as likely as non-disabled people to live in relative poverty; they are less likely to be in work, less likely to have savings and less likely to own their own homes. If an individual requires social care services throughout their life, and is subject to a charging regime that can take their savings and capital into account, then it can be practically impossible for them to build up assets. As the government attempts to address the ‘savings disincentive’, whereby older people may have to sell properties and assets to fund care, it is vitally important that it does not move towards a funding mechanism that overlooks the very different financial situation that some younger disabled people can face. If people with lifelong, ‘high level’ social care needs were required to pay for a certain percentage of their care package, for example, this could drive this group even further towards poverty. If the burden falls instead on individuals’ families then there is a risk that the system could simply ‘penalise’ any family with a disabled relative. Making sure that the needs of both those who require care throughout life and those who only have social care needs late in life are fully considered and supported will be critical in ensuring an equitable system.

FACS is unfair. Regardless of the total level of social care funding, the way that social care funding is allocated through FACS needs to be reformed. In our survey, 71 per cent of people disagreed with the statement ‘I think that the current needs-based eligibility criteria are fair’; and 49 per cent of people surveyed disagreed with the statement ‘Social care generally reaches those who need it’.

Part 4: Social care pledges to carers and families

Increase the support available. Around 90 per cent of our questionnaire respondents felt that insufficient support is offered to informal carers. Of people with multiple sclerosis, only 13 per cent felt that the government provides adequate help to their friends and family members who give them care and support. Many people who assume informal caring responsibilities can be forced to leave work, leading to significant drops in household income. At the same time, Leonard Cheshire Disability's report *Your Money or Your Life* described the impact that assuming caring responsibilities can have in terms of changes to personal relationships, with people worried, for example, about the effect on young children of being forced to become carers for their disabled parents.²²

Part 5: Social care staff pledges to you

The most important duty for social care staff was that they should treat people who use services as a person, not as a disability. This implies taking into account their whole life circumstances. It was also important that service users were recognised as being in charge, being the expert on their condition and being treated as a paying customer.

3 the case for a constitution

All public services are a deal, an agreement between us, the citizens, and the state which represents us: that certain services will be paid for collectively and available freely by those who need them. Through our NHS, free health care is available for anyone who needs it, irrespective of how rich or poor they are in exchange for general taxation. Whether we need or use the NHS ourselves, we recognise its importance for the well-being of our society and the principle of collectively providing for those who need it.

Social care is also an essential public service. But there is no 'deal' for social care. Unlike other important public services it is not free for all for those who need it. It is heavily rationed, so only those people with the most serious needs receive publicly funded help, leaving thousands without the support they need. It is also means tested, so people with often very limited savings and assets must contribute to the cost of their own care. Partly as a result, tens of thousands of people depend primarily on the support of family and friends, which can strain these relationships, and prevent these 'informal carers' from enjoying full and active lives of their own.

Social care is there for all of us, but there is no broad consensus about what help people might expect to receive, and at the moment the level of help given varies wildly depending on where you live. The way social care is delivered can be complicated and the system itself difficult to navigate. The legal framework for adult social care is widely recognised as inadequate, incomprehensible and outdated: a confusing patchwork of often-conflicting statutes. It lacks a single, modern statute that underpins the key values and principles of adult social care – a clear resource that service users, carers and social care staff can consult to understand whether services can or should be provided and, if so, what kinds of services.

That is why social care needs a deal. It needs to be put on the same footing as other public services. As a society

we must reach a deal with the state as to what support we expect and what we will contribute in return. Throughout our research there was strong support among workshop participants for the idea of a constitution which could set this out. Based on the concerns and aspirations of social care service users, this constitution outlines the framework for that deal. It is an aspiration, but founded on the principles of fairness, opportunity and equal citizenship for all. The constitution is aimed at setting out clearly the rights and responsibilities for two constituencies: those who use social care services currently and those who might, one day in the future, need to use them – which could be any of us. Therefore it is a mixture of general principles and specific concrete pledges and rights.

At its core, we believe everyone – including friends or family who decide to care for others – should have the opportunity to live a full and active life, to be in control of their lives and to take a full part in family, social, cultural and economic activities. In other words, everyone should have the opportunity to be a full and active citizen. For those who face barriers to this because of a disability, impairment or old age, we believe the state should offer the support they need to realise that opportunity. No one should be denied this opportunity because they cannot afford to pay for support they need, and although some people may contribute some of their own money towards the cost of their care, this should never act as a disincentive to work or save, or undermine their full and active lives.

In exchange, citizens should fund this guarantee through general taxation, recognising that, just like the NHS or education, social care is a vital public service to create a happier, healthier and fairer society.

The outcomes that social care is currently judged against are broadly useful as a set of indicators for someone's ability to live a full and active life.²³ They are health and emotional well-being, improved quality of life, making a positive contribution, exercising choice and control, freedom against discrimination or harassment, economic well-being, and personal dignity and respect. We believe it is important that these outcomes remain intact and at the forefront of the social care transformation. These are goals that should be facilitated by the care system in relation to older people, people with disabilities and anyone needing care support, as well as their families and carers.

In a flourishing welfare state, for an active citizenship model to flourish, it is clear that citizens who require care and support from the state should be able to access it – regardless of level of means or need. For those who face barriers to this because of a disability, impairment or old age, the state should offer the support needed to achieve that. No one should be denied this opportunity because they cannot afford to pay for it.

From the starting point of active citizenship, where everyone can be included in political, economic, cultural and community activities, many other principles follow.

The ten principles of the constitution

Starting with the principle of citizenship, below we give an explanation of all the outcomes that form the crux of the constitution. The vision can be summarised by ten principles, which determine the way central and local government and other publicly funded bodies should act to meet the needs of people who require support.

I Citizenship

Everyone has the right to live a full and active life. This means being in control of one's life, and having the opportunity to participate fully in family, community, cultural, political, social and economic activities. This is known as 'full and active citizenship'.

Insufficient value is attached to services and no positive role established for how care and support for citizens can facilitate greater participation and economic involvement or help avoid benefit dependency.²⁴ That is why the concept of citizenship is so important. Citizenship is a fundamental concept to our democratic society and assumes a set of rights and responsibilities from state to citizen – and vice versa. Being a full and active citizen, however, involves more than simply recognising the legal commitment between governments and individuals. In fact, it is a much more comprehensive concept collating formal and non-formal, political, cultural, autonomous, community and caring activities. Therefore the role that citizenship can play is twofold: first, the governmental realm has the duty to protect the individual – especially those members of society who face greater hardship, or are in the most delicate situations. Second, there must be an acknowledgement of the social and communitarian aspects of being a fully active citizen:

Citizenship is socially embedded: an individual's identity is influenced through their relations with others [and] the very notion of an active citizen may be compromised by the opportunities that citizens have to exercise influence and to play an active role in society. This compromising may reflect differences in social, health, disability, age, gender and economic position and status within a society. Depending on who they know, how they are respected and viewed by those in more powerful positions, many citizens – regardless of their legal status – may be outsiders and marginal to the key decisions that impact on their lives.²⁵

Disabled individuals have fought a hard battle to gain equal citizenship as other members of society. They are often considered ‘net takers’ instead of active contributors to society, and they have been excluded from the full rights and responsibilities of citizens.²⁶ Living independently is part and parcel of citizenship, as is the ability to live a full and active life. Members of society who receive social care services cannot be seen as passive recipients – not only because all citizens receive state services in one form or another, but because they have the right to engage in every aspect of community life.

Everyone currently using care services, and those who will need to use them in the future, ought to be assisted by the state, in order to be active in all aspects of political, cultural, economic and social life if they need it because of old age, disability or impairment. It will help people maintain their independence and dignity, while enabling them to remain even if they receive social care.

II Equality

Anyone who needs support to live a full and active life because of a disability, impairment or old age has the right to a sufficient level of support and care that gives them the opportunity to live this life, whether those needs are temporary or permanent. This includes families and friends who care for other people.

Equality is understood as the state’s broader role in creating a more equal, fair society, by trying to ensure that individuals have an equal opportunity to thrive within that society. Where circumstances exist that are beyond a person’s control and they impinge on that person’s ability to thrive, the state should facilitate their capacity to do so. True equality exists in a society that seeks fairness in the freedoms that people have to lead fulfilling and meaningful lives of their choosing. The role for the state is to protect and promote substantive opportunity to do this. When asked ‘What should social care be there to achieve?’, respondents overwhelmingly said they thought it should achieve equality.

In this context, we include those people who choose to care for someone. As it stands, their active citizenship is often put at risk because of their decision to assist someone else.

III Access and eligibility

No one will be denied this opportunity [to lead a full and active life] because they cannot afford to pay for the support they need. Some people might contribute to the cost of their own care, although it will not be done in a way that discourages people from working or saving, and any contributions made will not undermine people's full and active lives.

At present there are thousands of people who need support in order to be active citizens – but they cannot afford it. No one should go without the support they need to live full and active lives if they can't afford it. There should be a basic minimum level of support freely available to everyone who needs it, regardless of their level of need or ability to pay.

At some level all public services need to have some form of eligibility testing, to ensure that only people with genuine needs receive publicly funded support. However, the current needs-testing system, which excludes large numbers of people with serious needs, should not be used for this purpose.

This does not necessarily mean that there should not be some type of means testing. It is worth noting that throughout the workshops many participants stated that they thought that people who have abundant or necessary means to pay for their care ought to make a financial contribution. Although in the current climate it is clear that some people might be expected to contribute to the cost of their own care, any payments made in this way should not discourage people from working or saving, and any contributions made will not undermine people's full and active lives.

IV Friends and family

Social care supports caring relationships. It is right that friends and family support each other when needed. However, friends and family members will not be expected to compromise their own full and active lives because they have chosen to support someone.

Unpaid carers must be at the heart of any social care transformation. At any one time 1 in 10 people in Britain is a carer, and 6,000 people take on caring responsibilities every day. These are usually family members.²⁷ These people decide to perform critical roles in families and communities.

They provide physical support, emotional assistance, and help with day-to-day activities, often at great cost to themselves, and the overwhelming majority receive no support from the state. However, this role should never come at the expense of other important elements of the carer's life. Friends and family, in other words, must also exercise free and active citizenship. Although they should not be discouraged from carrying out their caring role, it should not be assumed that people will take on this role and those who do should not be penalised for doing so.

The government and a number of analysts have acknowledged the important contribution made by unpaid carers, and there has been a growing realisation that carers have needs—signalled by the recent Carers' Strategy, which increased funding available to carers.²⁸

V Equity

People's right to live a full and active life will not depend on where they live geographically, or whether they live at home or in an institutional setting.

Throughout the workshops there was frustration about the different care packages available (and respective prices for them) across England. Social care suffers from a number of different postcode lotteries: the differing application of the FACS framework, resulting in people having various degrees of access to support and the lack of 'portability' of assessments; a big range in the charges levied for non-residential services; and wide variations in the type of support offered to carers and the provision of open access services, and so on. Service users could not understand how to transfer their care package if they moved to a different borough or town, which further complicated their lives.

In the constitution we propose that a principle of equity should be in place where one's well-being and right to full and active citizenship does not depend on where one lives. This would be partly achieved by ending the system of needs testing, and through a tighter central regulation of local variations in fees.

VI Choice and control

Those who require social care support, together with their friends and family, have the right to control how their needs are met, and to decide how that support is managed and

delivered. They have a right to be involved in decisions that might affect their lives.

Social care must be committed to delivering services that are designed around the life of the person who needs it. Our research and others have found strong support among service users for having control over the type of services they receive and how they are managed. This is shared by just over half of prospective service users, too: in a study of people who do not yet receive care, commissioned by Counsel + Care, 56 per cent of respondents stated they had a preference for receiving a cash sum direct from their social services department, enabling them to arrange their own social care.²⁹

Therefore, social care services should reflect the views, aspirations and preferences of people using the services in the best manner possible, including every user's right to access a personal cash budget if they choose to. Service users must be at the centre of all service development and will be involved in all the decisions taken about their care package, as well as system design more broadly.

To make choices about their care, people need access to information, support and advice about how to do so in the best way. This means the information and advice for people – including those who do not use publicly funded help – needs to be available.

VII Independence

Social care prioritises support that can help people maintain their personal and family's independence wherever feasible, and enables them to live a full and active life.

People do not want to be dependent on institutional care or the support of others to live their lives fully. Research on the subject shows that people prefer to live in their own homes for as long as possible.³⁰ Where feasible, therefore, social care services should be aimed at supporting people to live at home, and should invest in early intervention services, which can help people stay at home and live independently as long as possible.

VIII Meeting people's needs

Social care recognises that people face different and changing barriers to living a full and active life. Everyone will need something specific to their own life and circumstances.

Therefore the aim of the social care is not to provide a set service, but to achieve positive improvements in people's lives, however that is best achieved. To know how far this is working, success will be measured against seven outcomes.

All services should be geared to meet the following outcomes: health and emotional well-being, an improved quality of life, the ability to make a positive contribution, the ability to exercise choice and control, freedom against discrimination or harassment, economic well-being, and personal dignity and respect. However, there needs to be recognition these outcomes can only be met if services are personalised.

IX Openness

Social care is a public service, and is accountable to the public, communities and the people who use its services. It is open and transparent in every aspect of its work.

Information, innovations and transformations should be shared with the wider public, and all decision making should be open and transparent. It should include information about resource allocation systems (the way personal budgets levels are set), total local authority social care budgets and local commissioning decisions. This information should be available to everyone, whether they are eligible for publicly funded support or not.

X Responsibility

Leading a full and active life also depends in part on people playing an active role in making it happen, by making the best use of the resources they are given, and where possible sharing what they have learned with others.

Citizenship presumes there is a two-way relationship between the state and individual. Social care users have rights and responsibilities and should do their best to keep the system healthy and efficient. As part of their responsibilities, citizens have an unspoken duty to inform others of best practice approaches and services that have proved successful, and to tell others about networks and peer groups. There is growing recognition that if one is to achieve positive outcomes in one's life one needs to be actively engaged.

Costing calculations

Building a system based on the principles we have set out in this constitution will almost certainly cost more than is currently spent on social care. The current social care system in England as a whole costs the public purse around £14.2 billion in 2006/07.³¹

It is important to make some estimate of how much more a system set out according to the ‘active citizenship’ principles discussed here would cost. Despite considerable work being done on projections for how much social care services would cost for older people in England under various scenarios, similar projections for the whole of social care have not been made.

Accurately calculating the cost of a system based on achieving active citizenship is difficult for three main reasons, and is ultimately beyond the scope of this work. First, there are no figures available for how many people with physical and learning disabilities in England are not accessing services because they are excluded through the current needs and/or means-testing system.³² Under the active citizenship model, it is likely that there would be an increase in the numbers of ‘low’ and ‘moderate’ needs groups eligible for public funding. However, without accurate figures, it is difficult to make estimates.

Second, trying to calculate the average care package cost for these individuals is problematic. The current average cost per care package (across all user groups) is £11,667 per annum. However, it is probably fair to assume that many of the newly eligible individuals under a new system would tend to have lower care package costs, although it is not obvious by how much. In addition, with the implementation of personal budgets, and the resetting of budget levels through locally set resource allocation systems, average care packages are likely to change further.

Finally, it is likely that implementing an active citizenship model would require a new set of eligibility criteria to replace the current FACS framework, possibly in line with the system suggested by CSCI in its recent review of FACS.³³

Therefore, accurate costing figures would require a study comparable to the Wanless Review,³⁴ but it is possible to use this review to make some extrapolations. Wanless

estimated that the introduction of free social care for older people would cost between £1.7 billion and £4.2 billion, depending on whether money currently spent on Attendance Allowance and Disability Living Allowance was redirected. This was based on a 'partnership' model, where free care is available up to a point for all, beyond which further care could be means tested in some way. Wanless set this at the equivalent of high dependency package, or 66 per cent of a benchmark care package; our benchmark would be the achievement of the outcome of active citizenship. Beyond that point, individuals then make contributions matched by the state. Those on very low incomes would be supported in making additional contributions through the benefits system.

Extrapolating from Wanless, older people make up 43 per cent of the total social care budget (in 2006/07), with the physical (7 per cent), learning (16 per cent) and mental health (5 per cent) groups making up 28 per cent. Assuming similar percentage increases in expenditure across all groups – following Wanless – would mean there was an increase of just over £1 billion for these groups. However, the average care package cost for disabled users is around 60 per cent higher than for older people, so we might estimate very roughly that free social care to other groups would cost an additional £1.6–4 billion.³⁵ Added to the older people estimate, there would be an increase of £3.3–8.2 billion in 2007 prices.

However, the active citizenship model would also imply increasing massively the support available to carers. Indeed, there is general agreement that the current levels of support, financial and otherwise, for unpaid carers is inadequate.³⁶ The funding requirements in this group have not been considered in great detail. Work by Carers UK suggests that increasing Carer's Allowance from £50.55 per week to £90.70 would go some way to alleviating the difficulties carers currently face. This would result in an increase in the total public spend on carers of around £900 million.³⁷ This figure is likely to increase further because it only considers those currently receiving Carer's Allowance – and there are a large number of people who are probably eligible but do not receive it. However, that figure is difficult to calculate precisely.

On these assumptions, the total increase in expenditure is likely to be between £4.2 and £9.1 billion. It is worth

noting, however, that a new funding settlement would also offer potential savings in the long run, for example by keeping people in work, helping families from reaching crisis point, and allowing disabled and older people to contribute more economically.

Precisely where this additional money would come from – whether general taxation or specific insurance models, for example – is not something considered here. There are a number of possible options that have been considered in detail elsewhere.

The case for change is strong. In 2007, the Caring Choices coalition surveyed over 700 people about the future of social care funding, and 99 per cent of respondents believed more money needs to be spent on long-term care regardless of where that money comes from – and that some kind of partnership between the state and the individual was the most popular approach, with the state guaranteeing some minimum entitlement to all individuals at point of use.³⁸ This matches our findings on the subject.

conclusion

The debate on the future of adult social care in England is crucial not only to people who are using social care services but also to those who are not. The government is currently considering how a new settlement for social care might look. At the same time the Law Commission is reviewing adult social care law with a view to creating a single statute outlining whether services can or should be provided and setting out principles to guide interpretation and understanding.

The social care constitution sets out that any new settlement for social care should be based on the principles of citizenship, equality and fairness. Social care should be a truly empowering public service for all who need it, one that tackles and removes the barriers that some people face in their everyday lives. Everyone should have the opportunity to take part in their communities and be able to live the lives they want to lead.

The constitution sets out how this can be achieved. Adopting it would help provide clarity for the public, local authorities, social care providers and staff, and critically for users of social care services about what the social care system can provide. We urge the government to recognise and adopt the constitution as a set of guiding principles for our social care system.

We recommend that the Law Commission uses this social care constitution to recommend the creation of a clear set of legislation for adult social care based on the principles of citizenship, equality and fairness, and sets out in detail what everyone should expect from social care services if they need them. The complexity of the social care system is a major barrier to the government's plans for independence, choice and control. Many people do not understand how the system is funded, who is entitled to support, and how the system works.

Ultimately, higher political priority needs to be given to social care through the political and public recognition of the crucial role social care services play in our society, and by committing more resources to the social care system. In the context of the government's current review of social care funding, this includes resourcing social care to ensure that social care support is given to everyone who needs it.

Annex 1 MS Society questionnaire

Executive summary

As part of the MS Society's response to the Department of Health consultation *The Case for Change*,³⁹ the views were gathered of a large number of people affected by multiple sclerosis, and their carers. In September 2008 questionnaires were sent to a random sample of 1,500 members of the MS Society who identified as having multiple sclerosis – one questionnaire was to be completed by the person with multiple sclerosis and one by a family member or friend who provided a significant amount of care. There was a high response rate of 42.3 per cent (635 of 1,500 questionnaires sent) among people with multiple sclerosis, and 454 carers (the number of carers who received the survey is not known).

Key findings

The current care and support system is not well understood:

- 60 per cent of respondents stated that they did not understand what care and support services they are entitled to.
- 68 per cent stated that they did not know how much they would be expected to pay towards these services.

There is support among people affected by multiple sclerosis for a universal care and support service, providing an appropriate level of services, regardless of wealth, level of need or location:

- 96 per cent of respondents felt that people with multiple sclerosis should be entitled to the same services wherever they lived in the country.
- 86 per cent of respondents felt that everyone should be guaranteed appropriate services regardless of wealth.
- 86 per cent felt that people with all levels of needs should receive services.

Respondents thought that services for people with fluctuating conditions need to be developed:

- 95 per cent of people with multiple sclerosis felt that better services during a relapse or sudden deterioration of their condition would help them maintain their independence.
- 91 per cent of stated that they were the main giver of care and support during a relapse or sudden deterioration of their friend or family member's condition.
- 91 per cent of carers felt that services to provide help during relapses would help them to balance caring with other aspects of their lives.

People with multiple sclerosis find it difficult to plan for their future:

- 81 per cent of respondents with multiple sclerosis felt that their condition made it difficult to save for their future care needs.
- 81 per cent of respondents with multiple sclerosis felt that they would like the opportunity to plan their care and support in advance.

People affected by multiple sclerosis are not satisfied with the help on offer to carers:

- 73 per cent of people with multiple sclerosis did not feel that their support networks received adequate help from the government.
- 71 per cent of carers did not feel that the government was helping them to provide care and support.

Table of results

Variable	Average [*]	Strongly disagree [*]	Disagree [*]	Neither agree nor disagree [*] Ensuring the care system delivers for people with MS (people with MS only)	Agree [*]	Strongly agree [*]	Total number answered
Ensuring the care system delivers for people with MS (people with MS only)							
It is difficult to save or plan for future care needs	5	2%	4%	13%	24%	58%	629
Would like to plan care and support services	4	2%	2%	15%	32%	49%	624
Services during relapse would help maintain independence	5	1%	0%	4%	23%	72%	627
Ensuring the system is clear							
Understands care entitlement	2	33%	26%	15%	14%	12%	1064
Understands how much required to pay towards services	2	44%	24%	15%	9%	8%	1063
PwMS should be entitled to the same services wherever they live	5	2%	0%	2%	7%	89%	1073
Increasing resources in the care system							
Home/savings should be used to pay for care	1	69%	17%	10%	2%	2%	1059
Proportion of income/benefits should be used to pay for care	2	48%	16%	19%	14%	4%	1062
Taxation should be increased to pay for services	3	17%	10%	27%	21%	24%	1062
Who should get services?							
Only people on low incomes should receive services	1	60%	19%	10%	5%	6%	1061
Everyone should be guaranteed services regardless of wealth	5	4%	3%	7%	19%	67%	1065
People with all levels of needs should get services	5	2%	3%	8%	21%	66%	1067
Only people with high needs should get services	1	54%	25%	10%	5%	6%	1064

*1 strongly disagree

2 disagree

3 neither agree nor disagree,

4 agree

5 strongly agree

^ Results may not sum to 100% due to computer rounding

Variable	Average [*]	Strongly disagree [^]	Disagree [^]	Neither agree nor disagree [^] Ensuring the care system delivers for people with MS (people with MS only)	Agree [^]	Strongly agree [^]	Total number answered
Support networks of people with MS (people with MS only)							
Support networks receive adequate help from Government	2	45%	23%	17%	8%	4%	442
Would like care from professional care workers	4	6%	7%	16%	15%	57%	444
Would like care from support network, paid by Government	4	5%	19%	33%	17%	17%	446
Support for carers (carers only)							
The Government is helping me to provide care/support	2	48%	23%	17%	8%	4%	442
Would like to provide care, but paid by Government	5	5%	7%	16%	15%	57%	444
Would like professional care staff to provide care	3	13%	19%	33%	17%	17%	446
Ensuring the care system delivers for carers and families of people with MS (carers only)							
Main giver of care and support	5	3%	1%	5%	16%	75%	444
Services during relapse would help balance life	5	1%	1%	7%	24%	67%	442
Supporting a PwMS means it's difficult to plan future	5	3%	5%	13%	19%	60%	445

*1 strongly disagree
2 disagree
3 neither agree nor disagree,
4 agree
5 strongly agree
^ Results may not sum to 100% due to computer rounding

Notes

- 1 CSCI, *The State of Social Care in England 2007-08*.
- 2 Wanless, D, *Securing Good Care for Older People*.
- 3 People in nursing homes have a flat rate payment (£101 per week for 2007/08) made by the NHS to contribute towards the nursing costs.
- 4 CSCI, *The State of Social Care in England 2007-08*.
- 5 NAO, *Personal Social Services Expenditure and Unit Costs England*.
- 6 CSCI, *The State of Social Care in England 2007-08*.
- 7 Henwood and Hudson, *Lost to the System?*
- 8 Greenhalgh et al, (2008) *Disability Review 2008*.
- 9 Foster et al, *Your Money or Your Life*.
- 10 Quoted in IPPR, *Care in a New Welfare Society*.
- 11 Carers UK, *Carers in Crisis Report*.
- 12 CSCI, *Cutting the Cake Fairly: CSCI review of eligibility criteria for social care* (London: Commission for Social Care Inspection, 2008)
The overwhelming majority (96 per cent) of respondents to an MS Society survey felt that people with multiple sclerosis should be entitled to the same services wherever they live in the country.
- 13 Spencer-Lane, 'Single statute for adult care services to replace outdated laws'.
- 14 CSCI, *Cutting the Cake Fairly*.
- 15 Ibid.
- 16 Social Insurance and Allied Services, *The Report to Parliament on Social Insurance and Allied Services*, the Beveridge Report.
- 17 DoH, *The National Health Service Constitution*.
- 18 They were open-ended questions, and so the answers given with accompanying percentages are the closest approximation of people's responses.
- 19 Chapman, *Systems Thinking*.
- 20 CSCI, *Cutting the Cake Fairly*.
- 21 Caring Choices, *The Future of Care Funding*; see also Local Government Association, 'Kiss goodbye to inheritance, kids told, as reality of care costs hits home'.
- 22 Foster et al, *Your Money or Your Life*.
- 23 CSCI, *New Outcomes Framework for Performance Assessment of Adult Social Care*.
- 24 NCIL, *NCIL Response to National Debate on Care and Support Reform*.
- 25 Taskforce of Active Citizenship, *The Concept of Active Citizenship*.
- 26 Brechin et al, *Care Matters*.
- 27 DoH, *Carers at the Heart of 21st Century Families and Communities*.
- 28 Ibid.
- 29 Help the Aged, Counsel + Care and Carers UK, 'Right care, Right deal', 2008.
- 30 See for example Bowers et al, *Making a Difference Through Volunteering*.
- 31 CSCI, *The State of Social Care in England 2006-07*.
- 32 Pickard, *Informal Care for Younger Adults in England*.

- 33** CSCI, *Cutting the Cake Fairly*.
- 34** Wanless, (2006) *Securing Good Care for Older People*.
- 35** The 60 per cent figure is based on National Statistics data on 2006 social care costs, which gives the average unit costs for various aspects of care for older people and other groups. However, the percentages here are not weighted, which would be essential to make these calculations more approximate. Averages (per week) are as follows: older people residential: 446; other groups residential: 760; older people home care: 129; other groups home care average: 196; older persons direct payment: 143; other groups direct payment average: 159; older persons day care: 77; other groups day care: 171. This figure does not consider the fact that disabled adults are more likely to be lower need groups, and so the cost might be slightly lower.
- 36** Caring Choices, *The Future of Care Funding*.
- 37** In May 2008 there were 404,320 people receiving Carer's Allowance in England. At £90.70 per week this would result in a total spend of £1.90 billion, compared with £1.06 billion at present.
- 38** Caring Choices, *The Future of Care Funding*.
- 39** DoH, *The Case for Change*.

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Social care is an essential public service. It provides day to day support for disabled people, those with impairments, and older people who need help maintaining their independence and living full and active lives. At the moment, it helps support over 1.5 million people, and it is a fundamental element of our welfare system.

With an increasingly ageing population and a growing complexity of care needs, our social care system needs a profound transformation to be sustainable and fair. The current system lacks clarity, simplicity and fairness, making it extremely difficult to navigate and understand.

Demos has partnered with Leonard Cheshire Disability and the Multiple Sclerosis Society to investigate what disabled people of working age need from the social care system and how the future funding of social care can be designed to meet that need.

People requiring care services, providers and the general public should confidently understand what they can expect from the social care structure now and in the future. This report, and the accompanying Constitution, sets out a clear set of principles explaining what we should expect from the system and what we might be responsible to contribute in return. It defines a fair settlement between service users with the rest of society.

MS

Multiple Sclerosis Society



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