

# a constitution for social care

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## Contents

	Preamble	6
1	Principles that guide social care	10
2	What social care pledges to you	12
3	Your responsibilities to social care	16
4	Social care pledges to carers and families	18
5	Social care staff pledges to you	20

# Preamble

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, the report to the Parliament on *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. Today, an evil as great as any of these is lack of care.

Society has changed since then. In 1942, shorter life expectancy and the social concerns of the day meant that supporting older people and disabled people did not figure. Today we face a new set of challenges and opportunities. As our population ages and treatments develop, people's needs and disabilities have grown more complex. And our aspirations to support people who need care have also grown – we no longer accept that disability need be disabling. But the welfare state has not moved on. Social care remains poorly understood, undervalued and underfunded. For many it is remote and increasingly inaccessible.

It should not be like this. Social care is an essential public service. It provides day to day support for people with disabilities or impairments and older people, helping them live full, independent and active lives. It ranges from full time care for someone with a complex physical and learning disability, to help for an older or disabled person with daily activities like washing or cleaning. It includes support for those providing care on an informal basis. At the moment, it helps support over 1.5 million people.<sup>1</sup> It is just as important to the health and well-being of the country as the National Health Service.

Care will affect most of us at some point in our lives. It should be there for all of us when we need it. But unlike other important public services it is not free at the point of delivery for those who need it. It is currently delivered through a

combination of means and needs testing. On the means testing side, people with very limited savings and assets must often contribute substantially to the cost of their own care, driving them to the edge of poverty. On the needs testing side, because of chronic underfunding, care is heavily rationed and often it is only those people with the most critical needs and fewest personal resources who are eligible for publicly funded help. This leaves hundreds of thousands without the support they need, and they are struggling to survive.<sup>2</sup>

Varying interpretations of the needs criteria have also led to a postcode lottery. Unlike other postcode lotteries, it's 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, or receiving no support whatsoever: three-quarters of local authorities only provide services to people with the most serious needs. Partly as a result, the whole system relies heavily on the goodwill of families and friends who become unpaid carers to support loved ones, at the cost of their own independence and well-being.

Social care provision lacks the clarity of the principles of the National Health Service. This constitution for social care sets out a clear set of principles explaining what we should expect from the service and what we might be expected to contribute in return. The Constitution is openly aspirational, and includes specific and concrete pledges and rights, which should act as a useful set of operating principles for people who might come to use the service, making it clearer and easier to navigate.

Social care needs to be based on the principle of equal citizenship. Everyone should have an equal opportunity to live a full and active life, to be in control of one's own life and home, and to take a full part in family, social, cultural, economic and community activities. If you have a disability, or are an older person, or make the decision to care for someone, you should still 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, 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.

Of course, as with any publicly funded service, there are resource constraints. In the current climate, we accept that people who can afford it might reasonably be expected to contribute to the cost of their own care. However, any system of contributions must seek to minimise disincentives for people to work or save, and not undermine people's chance to lead a full and active life. There are other responsibilities for people who use the service too, such as recognition that improvements also depend in part on people playing an active role in making them happen.

Building a system based on the principles we have set out in this constitution will almost certainly cost more. It is difficult to estimate exactly how much that will be, partly because there are no accurate figures on how much people spend on their own care, and how many people are currently going without.<sup>3</sup> The current social care system in England as a whole costs the public purse around £14.2 billion every year, and it is likely that reform along the lines suggested here would cost an additional £5–10 billion a year.<sup>4</sup> Precisely where this additional money would come from – whether general taxation or specific insurance models for example – is not something considered here. However, it worth noting that such an increase would amount to just 10 per cent of the total NHS budget.<sup>5</sup>

On this footing, social care can become a truly empowering public service, one that tackles and removes the barriers that some people face in their everyday lives, and ensures that everyone has the opportunity to take part in their communities and are able to live the lives they want to lead.

# 1 Principles that guide social care

Social care exists to support disabled people, people with impairments, and older people who need support to live full and active lives. It is organised and driven by the following principles:

## 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'.

## 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.

## III Access and eligibility

No one will be denied this opportunity because they can not 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

## 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.

## V Equity across the country

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.

## 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.

## VII Independence

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.

## 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.<sup>6</sup>

## 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.

## 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.

## 2 What social care pledges to you

If you ever face barriers to living a full and active life because of a disability, impairment or old age, this is what you can expect:

- *Social care exists to support people to overcome the barriers that they face to living a full and active life because of a disability, impairment or old age and to ensure that they have an equal chance to achieve their goals*
- *No one will be denied the opportunity to live a full and active life because they cannot afford the care and 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*

### Access to services

- If you do not have the opportunity to lead a full and active life because of a disability, impairment or old age, you have the right to support that helps you do so.
- You might be asked to contribute something to the cost of this support if you can afford it. But the funding system for social care reflects the outcomes that social care is there to achieve. This means that it will not be set up in a way that actively discourages or prevents anyone who wants to live a full and active life – including working, saving or buying their own home – from doing so.
- Friends and families have the right to make their own contribution to support you, without that decision affecting the amount and type of support you are entitled to from the state.
- You have the right to sufficient and appropriate information and guidance to help you make choices about what you need, what you are entitled to, easy guidance on how the funding system works and advice on getting the things you need.
- You have the right to a named contact at your local authority who can offer guidance and advice to help ensure accountability and continuity.
- You have the right to access an independent source of information and advice near where you live and to have the peer support of people with similar needs.
- You have the right to be fully involved in the process of assessing your needs and aspirations. Any assessment will be designed around helping you achieve the things that are important to you and not how much money you have.
- You have the right to expect your assessment to be completed quickly and efficiently, and you have the right to expect any support you need to be made available quickly and efficiently.

- You will be given one assessment and only reassessed if the support you need changes. Assessments will not be repetitive nor place undue burden on you, or your family or friends.
- If your needs change, you have the right to immediate appropriate short-term help pending a permanent change to your care package.
- You have the right to access the full range of services that are publicly provided in your area to help people live full and active lives. In addition to social care services, they include transport services, cultural, education and social events, and leisure and sport activities. If they are not accessible to you, you can request that your local authority makes appropriate changes so that they are.

### Quality and type of care

- You have the right to know exactly what resources and support you are entitled to receive.
- Together with friends and family, you have the right to decide how your needs are best met and to decide how the support you receive is managed and delivered, including as a cash budget that you decide how to spend.
- You have the right to nominate a friend, family member or other person to act as an advocate to support you in getting the services that you need.
- You have the right to expect a wide range of local support services and options to choose from.
- You have the right to have the support you receive reviewed if it is putting you at undue risk or failing to give you the opportunity to live a full and active life. If resources are not being used to achieve appropriate aims, then the state will review the situation and take appropriate action.

- You have the right to complain about any aspects of the services you are unhappy with, and to appeal to an independent arbitrator if unsatisfied with the result or process.
- You have the right to expect your local authority to deliver services that conform to national standards and to encourage best practice within its area. If it does not you have the right to challenge the authority.
- You have the right to expect high standards of excellence and professionalism – in planning and delivering services, improving staff training, conducting pertinent research and in the management of services.
- Your local authority has a duty to manage the social care budget efficiently and in a way that maximises the money available to spend directly supporting people.

### Respect, treatment and involvement

- You have the right to be treated with dignity and respect.
- You have the right to be involved, directly or through representatives, in decisions made about local spending and service commissioning in your area.
- You have the right to know how much your local authority is spending on social care provision in your area, how the local authority calculates entitlements for different levels of need and how well your local authority is performing in helping people achieve their goals in life. Decisions made by the local authority will be taken in a clear and transparent way.
- You have the right to equal support irrespective of impairment, gender, race, age, religion or sexual orientation.

### 3 Your responsibilities to social care

Social care, like other public services, represents a deal between the public and the state. This section sets out the responsibilities of the general public and people who use social care services:

- *As a society we accept that social care is a vital public service and commit sufficient resources through taxation so the system is funded to achieve what has been set out in this constitution*
- *People who use social care support should make the best use of the resources they are given, and have the responsibility to share what they have learned with others*
- *Everyone has a responsibility to contribute to their own health and well-being and the health and well-being of others*

- You should always treat staff and personal assistants with respect, honesty and dignity.
- When explaining to the local authority what your needs are and what support you want, you should give honest and accurate answers about your impairment and your situation.
- You should keep anyone involved with your care updated about your needs. If your condition changes or improves, then you should report this honestly.
- You and those charged with your support should make sure that any care plan you agree to is designed to help you make sustainable and positive improvements in your life towards the goal of full and active citizenship. You should do your very best to keep to any care plan or package you agree to.
- You should give feedback to your local authority on staff matters and service provision, especially where you think that things can be improved.
- You should keep appointments or cancel with due notice.

## 4 Social care pledges to carers and families

It is right that friends and family support each other when needed. Social care will act in a way that supports caring family and friend relationships:

- *Families and friends have the right to choose to care for someone, but they will not be forced or unreasonably expected to do so. They will not be expected to give up work or compromise their own full and active lives*
- *If people decide to support or care for someone and this prevents them from leading a full and active life of their own, they have the right to support from the social care system to help them in their caring role and to maintain their own independence*
- You have the right to make your own contribution, financial or otherwise, and provide support to people you care about, without these decisions affecting the amount of state support that person receives.
- You have the right to a full and active life. If you have chosen to support someone and this compromises your own full and active life, you have the right to access support to help you maintain that. This includes being given information on assistance available for you, and training and personal development packages to help you in your role.
- If you care for someone, you have the right to a needs assessment by your local authority, which will take into account your whole life circumstances. You have the right to be fully involved in the process of determining what support you need. Any support will be designed to make sure you achieve the things that are important in your life.
- If you care for someone, you have the right to have appropriate breaks from your caring role.
- Children and young people will be protected from inappropriate caring roles. Young people who choose to undertake a degree of responsibility for caring must be able to make a fully free, active and informed choice to do so. There must not be an unreasonable expectation for them to do so. This decision must not compromise their rights, opportunity or potential as a young person.
- You have the right to be involved in decisions that might affect your life and the right to decide how any support you receive is managed and delivered.

## 5 Social care staff pledges to you

Social care staff includes social care workers who assess people's needs, personal assistants who help people with day to day living and local authority administrative staff. This is what you should expect from them:

- *Staff will treat you with honesty, dignity and respect throughout your dealings with them*
  
- *Staff have a duty to help you achieve the goals you have identified as important in your life*

- Staff and personal assistants will treat you as an individual with your own personal challenges and aspirations, not as a disability, impairment or condition.
  
- Staff will recognise that you are the expert on your own life and the support you need, and listen to your thoughts and opinions.
  
- Staff will be well informed about your needs, and knowledgeable about your condition and what it means for the support you need.
  
- Staff have a duty to provide you, or your chosen representatives, with simple, clear, and accessible information about the support they are providing you.
  
- Staff have a duty to inform you in advance of any likely changes in appointments, any changes to personnel, or any other arrangements that might affect you.
  
- Staff have a duty to protect your rights and promote your interests, and those of any unpaid carers.
  
- Staff have a duty to strive to establish and maintain your trust and confidence and that of unpaid carers.
  
- Staff have a duty to promote your independence.
  
- Staff have a duty to assist people in taking control of their lives, but where people need support or representation they also have a duty to make sure that the right system of support is in place.

## Notes

- 1 CSCI, *The State of Social Care in England 2006–07* (London: Commission for Social Care Inspection, 2008).
- 2 Ibid. At least 450,000 older people have some shortfall in their care and there are around 300,000 with needs who receive nothing at all. Comparable figures for adults with physical or learning difficulties are not available.
- 3 CSCI, *State of Social Care in England 2006–07*. See PSSRU, *Future Demand for Social Care 2005 to 2041: projections of demand for social care and disability benefits for younger people in England* (Canterbury: University of Kent, Personal Social Services Research Unit, 2008): there is no accurate evidence, for example, of the level of purchase of private care by adults of working age.
- 4 One aspect of our model suggests there has been an increase in the provision of care for people who are deemed to have ‘low’ or ‘moderate’ needs and are currently excluded from publicly funded care, although moving towards a citizenship model would invariably lead to a change in the eligibility regime used. Unfortunately there are no figures which indicate how many people that currently is, or indeed what the average cost per person would be. In *State of Social Care in England 2006–07*, CSCI estimates that older people in England spend around £5.9 billion privately on their personal care, and in *Securing Good Care for Older People* (London: King’s Fund, 2006) the King’s Fund suggested that an increase of around £1.7 billion would be sufficient to ensure care for all older people in England under a partnership model. Any increase of physical and learning disability service users accessing public funding is likely to be lower than for older people as they make up a smaller percentage of total service users, although average unit costs are considerably higher. For more details on costing please see our accompanying report.
- 5 HM Treasury, *Pre-Budget Report 2008: facing global challenges: supporting people through difficult times*, Cm 7484 (London: The Stationery Office, 2008). Taken from annex B: The Public Finances, table B18: Departmental Expenditure Limits – resource and capital budgets. The NHS budget for 2009 is £97.4 billion for England.
- 6 The following outcomes, as stated in the White Paper *Our health, our care, our say: a new direction for community services*, Department of Health 2006, will be used to measure how far that is being achieved: improving health and emotional well-being; improving quality of life; making a positive contribution; increasing choice and control; guaranteeing freedom from discrimination; promoting economic well-being; and maintaining personal dignity and respect.

**MS**

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