

# Northumberland's Joint Carers Strategy 2013-16



Carers, our expert care partners

## FOREWORD

The population in Northumberland is an ageing one, with more adults of pensionable age than the national average, alongside this, advances in healthcare means that people with significant health problems are living longer. Many of us will take on a caring role at some point in our lives, we may not recognise ourselves as such but this responsibility will take its toll.

Supporting carers makes good sense because they play a vital (unpaid) role in maintaining health and independence, building strong families and communities and preventing the need for services - but also because of significant risks to their health, wellbeing and future prospects in fulfilling this role.

According to the 2011 Census the number of people providing unpaid care in Northumberland has increased by 6% in the last ten years to almost 36,000. We also know that the greatest increase has been among those providing over 20 hours of care, the point at which caring starts to significantly impact on the health and wellbeing of the carer. This also impacts on the carers' ability to hold down employment as well as caring responsibilities, in turn having implications for the delivery of services in a sparsely populated county in which public sector organisations are major employers.

We have challenges ahead in trying to keep pace with rising need within a national landscape of economic change, and it is because of these challenges that we welcome this joined up approach to the delivery of Northumberland's Carers Strategy.

We are committed to ensuring a partnership approach to working with family carers, which fully recognises the value of carers both as partners in care and as people within our community with individual support and health needs.

The circumstances of every carer are unique, and we will strive to ensure that anyone living in Northumberland who has caring responsibilities, or is caring for someone living here, feels supported and valued.

**Daljit Lally, Executive Director, Adult Care, Northumberland**

**Paul Moffat, Corporate Director of Children's Services, Northumberland**

**Alistair Blair, Chief Clinical Officer, Northumberland NHS CCG.**

## Contents

Executive Summary.....	4
Introduction.....	5
National and Local Drivers	
Our vision	
Aims of the local strategy	
How will the strategy be used?	
Reporting structure diagram	
Who are carers?.....	10
Profile of carers in Northumberland	
Equality, work and health	
How have carers informed the strategy?	
Our Values and Principles of Practice.....	14
The Model of Comprehensive Carer Support.....	16
Key Commissioning Priorities .....	18
Priority 1: Recognition and Information	
Priority 2: Support	
Priority 3: Health and Wellbeing	
Priority 4: Financial Wellbeing	
Priority 5: Quality Services	
Priority 6: Having a Voice	
Joint Social Care and Health Commissioning Plan.....	23
Appendix 1: Policy Related Documents.....	24
Appendix 2: Glossary.....	26

<p>Our Vision</p>	<p><i>“Carers will be recognised and valued for the positive contribution they make to our community. The rights of all carers to a life beyond caring, to social inclusion and equal opportunities will be understood and facilitated. Carers will be involved and feel that in Northumberland the national vision for carers is delivered.”</i></p>			
<p>Carers Strategy Aims</p>	<p>National aims:</p> <ul style="list-style-type: none"> <li>➔ Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.</li> <li>➔ Enabling those with caring responsibilities to fulfill their educational and employment potential.</li> <li>➔ Personalised support both for carers and those they support, enabling them to have a family and community life.</li> <li>➔ Supporting carers to remain mentally and physically well.</li> </ul>	<p>Local Aims</p> <ul style="list-style-type: none"> <li>➔ Ensure the national strategy actions are achieved locally;</li> <li>➔ Inform all partner agencies of the issues important to carers;</li> <li>➔ Provide a framework for action for carers, setting out local priorities and direction for developing support for carers, thereby informing joint commissioning plans;</li> <li>➔ Improve and extend partnership working to benefit carers.</li> </ul>		
<p>Key commissioning priorities</p>	<p><b>1 Recognition and Information</b> Integral carers assessments; one-stop information; early identification; information resources; increased awareness of young carers.</p>		<p><b>2 Support</b> Flexible breaks opportunities; personal budgets; involvement in hospital discharge; good emergency planning; young carer focus through CAF.</p>	
	<p><b>3 Health and Wellbeing</b> Carers wellbeing Check; skills information and knowledge to care safely; access to counselling; GP awareness; support through transition; safeguarding approach.</p>		<p><b>4 Financial Wellbeing</b> Access to leisure, learning, work and volunteering; training access; benefits information and advice; ESF employability support.</p>	
	<p><b>5 Quality Services</b> Coordinated whole family support; choice of breaks opportunities; Carers Support Fund; involvement in user care planning; targeted services for young carers.</p>		<p><b>6 Having a Voice</b> Involvement at strategic level; links with Healthwatch; regular and quality feedback; involvement in individual care planning; safeguarding reporting; young carer voice.</p>	
<p>Monitoring</p>	<pre> graph LR     A[Local and condition specific carer network groups] --&gt; B[Carers Strategy Reference Group]     B --&gt; C[Carers Strategic Partnership Group]     C --&gt; D[Adult &amp; Children's Joint Commissioning Groups]     D --&gt; E[Health &amp; Wellbeing Board FACT]             </pre>			

## Introduction

Carers make a massive contribution to our community and should be recognised for the hard work they do every day. There are already more people in Britain over the age of 60 than there are children below the age of 16. In ten years, more people will be over 40 than below it. The demands on social care and health provision are increasing along with our odds of taking on the caring role for a loved one; in fact most of us can expect to be a carer at some point in our lives. We may take on the role suddenly and unexpectedly or gradually.

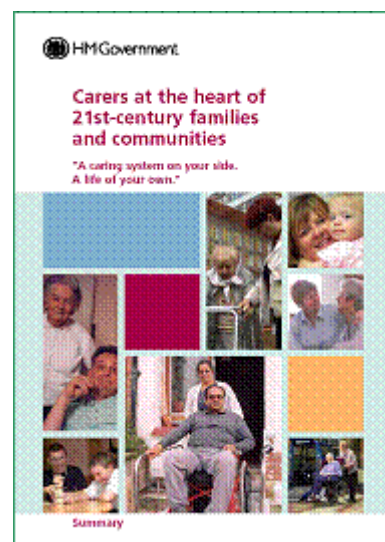
Not all carers live in the same household as the person they care for but all have taken on a major commitment to care for a dependent relative or friend on an unpaid basis, which has a significant impact upon their own lives. More and more people find themselves struggling to balance caring responsibilities with paid work and facing the prospect of having to sacrifice one for the other. Sometimes caring can be the most fulfilling thing in the world, sometimes it can be the toughest thing in the world. No two caring relationships are ever exactly the same.

Northumberland launched its first carers' strategy in June 2001, the result of collaboration between carers living in Northumberland and professionals from a range of statutory and voluntary agencies. Based on full consultation with carers, the strategy provided, for the first time, a clear framework for addressing carer priorities using the Carers Compass developed by the Kings Fund as a strategy tool. Northumberland Carers' Strategy has been particularly successful in raising the profile of carers and driving change. The strategy was formally reviewed in 2005 and again in 2008. This 2013-2016 Carers Strategy reflects new joint commissioning arrangement and changes in national and local policy, and provides an overview of the progress made in supporting carers and guiding further improvement and development.

## National and Local Drivers

***Caring about carers; a national strategy for carers*** was published in 1999, followed by a new national carer strategy ***Carers at the heart of 21<sup>st</sup>-century families and communities*** in 2008. This was then reviewed in 2010 after consultation. The document ***Recognised, valued, supported: next steps for the Carers Strategy*** sets out the Government's priorities for carers and identifies the actions they will take to ensure the best possible outcomes for carers and those they support.

The Department of Health has also published a guide on emerging evidence ***Carers and personalisation: improving outcomes*** which include examples to illustrate how the principles of personalisation have been applied, emphasising the value of finding ways forward that make sense and work best locally.



### Health and NHS Reform includes:

The NHS White Paper ***Equity and excellence: Liberating the NHS*** sets out the Government's vision for the future of the NHS and was the basis for the Care Bill. This says that *"The system will focus on personalised care that reflects individual's needs, supports carers and encourages strong joint arrangements and local partnerships"*

The **Care Bill**<sup>1</sup> was published in May 2013, though not yet through the parliamentary process and with regulations to be sorted, the new rights for carers proposed include among others:

- ➡ Removal of need to request an assessment, automatic assessment if the local authority considers the carer to have needs.
- ➡ Rights to services for carers following assessment.
- ➡ Right to be consulted on the assessment of the person needing care.
- ➡ Duty to promote the wellbeing of adults receiving care and of carers receiving support.

The **NHS Operating Framework** identifies carers as an area requiring particular attention, actively encouraging joint working across the NHS and local authorities, particularly in relation to agreeing local plans and providing carer breaks.

In April 2013 **Northumberland Clinical Commissioning Group (CCG)**, led by GPs, replaced the Primary Care Trust (PCT) and has a key role in ensuring effective support for carers from the NHS. The CCG is committed to joint commissioning with the local authority.

<sup>1</sup> Care Bill published 9 May 2013 and to be introduced to Parliament and the House of Lords from 4 June.

**Northumberland Health and Wellbeing Board** which produce the Joint Strategic Needs Assessment and the area's Health and Wellbeing strategy, has a duty to involve users, carers and the public.

The **NHS Constitution** (Section 4) requires that NHS services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment.

"The NHS commits to work in partnership with you, your family, carers and representatives." (Section 2a of the NHS Constitution)

Northumberland was involved as a **National Carers' Strategy Demonstrator Site**, a programme developed by the Department of Health as part of the commitments made in the 2008 National Carers' Strategy (HMG, 2008). The national report of the programme<sup>2</sup>, delivered across England and comprising 25 partnerships, reflects the evidence gathered as part of the Northumberland Health Check for Carers pilot and has led to the development of a sustainable Carer Wellbeing Check in Northumberland. The report also provides commissioners with policy recommendations.

## Our vision for carers in Northumberland is that:

***"Carers will be recognised and valued for the positive contribution they make to our community. The rights of all carers to a life beyond caring, to social inclusion and equal opportunities will be understood and facilitated. Carers will be involved and feel that in Northumberland the national vision for carers is delivered."***

To realise our vision we will aim to fulfill the national strategy actions, supporting its priorities to ensure the best possible outcomes for carers and those they support, including:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.
- Enabling those with caring responsibilities to fulfill their educational and employment potential.
- Personalised support both for carers and those they support, enabling them to have a family and community life.
- Supporting carers to remain mentally and physically well.

## Aims of the local strategy are to:

- Ensure the national strategy actions are achieved locally;
- Inform all partner agencies of the issues important to carers;

---

<sup>2</sup> New Approaches to Supporting Carers' Health and Wellbeing: Evidence from the National Carers' Strategy Demonstrator Sites Programme. CIRCLE. University of Leeds 2011

- ➡ Provide a framework for action for carers, setting out local priorities and direction for developing support for carers, thereby informing joint commissioning plans;
- ➡ Improve and extend partnership working to benefit carers.

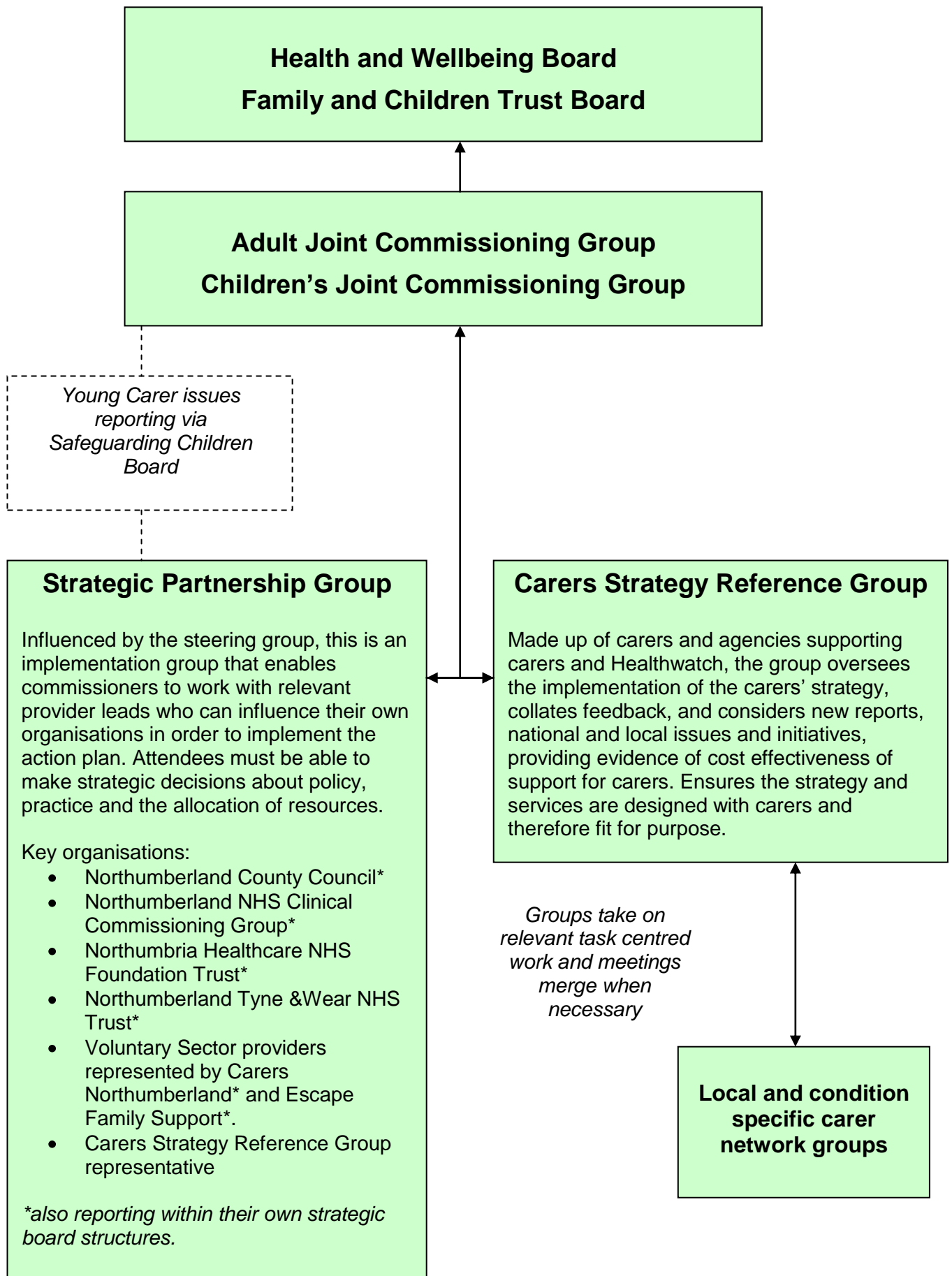
## How will the strategy be used?

The strategy is intended to give an overview of carers' issues and set out what we plan to do to achieve local priorities, building upon the progress already made. It recognises the enormous contribution Northumberland carers make to the lives of their friends and families; their needs and aspirations; and how we will work together as agencies and with carers themselves to achieve our goals in the next three years, taking into account social and demographic changes as they affect the population of Northumberland.

This strategy is accompanied by joint commissioning plans that will be monitored quarterly and reviewed annually. Joint commissioning plans will be updated and republished annually throughout the duration of the strategy. The strategy will also continue to evolve in response to national and local demands.



The diagram below illustrates the structure for the implementation of the joint carers' strategy in Northumberland.



## Who are carers?

**Carers** are people who provide emotional, physical and/or practical support to loved ones, relatives or friends because of disability, illness, or the effects of old age. They may also take responsibility for the care of a person who is experiencing mental distress or is affected by substance misuse or HIV/AIDS. The care they provide is unpaid. Family or friends will not always want, or be able, to be carers or to provide every aspect of care needed.

A **parent carer** is a parent or guardian who provides support in addition to usual parenting responsibilities because their child is ill or disabled. Parent carers will often prefer to be referred to as parents rather than carers, although they have rights under carer legislation.

A **young carer** is anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of someone, usually in their family. Many young carers assume significant levels of responsibility normally associated with an adult. It should not be assumed that all children whose parents are ill or disabled are automatically young carers; however, an increasing number of disabled and ill adults are forced to rely on their children for their survival and wellbeing, resulting in their children becoming young carers.

The main groups of **hidden carers** include:

- ➔ People who simply do not realise that, in the help they are offering, especially during periods of crisis, they are carers. The geographical isolation of many people in Northumberland increases this risk and rural carers are not only less likely to recognise themselves as carers and access their rights but may also experience greater difficulty getting the help they require;
- ➔ People providing considerable emotional support to someone with an enduring mental health problem, who because the care does not involve practical help often fail to recognise their eligibility for support and the strain caring places upon them before reaching crisis point;
- ➔ People supporting someone with a drug or alcohol problem; these carers find it difficult to share their concerns with others due to stigma and may not ask for help, yet the impact upon their own lives may be considerable;
- ➔ Young carers (under 18) are often not recognised by professionals as having a substantial caring role and can be extremely isolated;
- ➔ Black and ethnic minority carers tend to be hidden largely due to assumptions made with regard to the closeness of families and the role of women. There are arguments, however, that suggest this group are 'easy to ignore' rather than 'hard to reach'.<sup>3</sup>

---

<sup>3</sup> *Beyond We Care Too, Putting Black Carers in the Picture. The Afya Trust for the National Black Carers & Carers Workers Network 2008*

- ➔ Mutual caring amongst older families is increasing but often remains hidden. An increasing number of people with learning disabilities are providing regular and substantial care for their ageing relatives.

## Profile of carers in Northumberland

- ➔ Northumberland has a population of 316,000<sup>4</sup>, with considerably poorer health statistics than the England and Wales average. The health issues which create the most significant demand in Northumberland are in line with those creating most demand at national level – heart disease, stroke, cancer and mental health.
- ➔ Northumberland is fundamentally rural in nature – nobody lives in a settlement with more than 35,000 residents. The upland communities living within the North Pennines and Cheviot Hills are among the most remote in the country. In these places, getting to even fairly basic amenities – such as a shop or GP, much less day centres or hospital – may not be easy or straightforward and carers can find it difficult to obtain advice, help and assistance.
- ➔ Northumberland's population is also an ageing one – we have fewer children under 15 years old and more adults of pensionable age than the national average. This has implications not only for the increased number of family members taking on caring responsibilities but also on the workforce, many of whom will give up work to care.
- ➔ The number of people in Northumberland providing unpaid care has increased in the last ten years by 6%, to almost 36,000<sup>5</sup>.
- ➔ The greatest rise has been among those providing over 20 hours care – the point at which caring starts to significantly impact on the health and wellbeing of the carer, and their ability to hold down paid employment alongside their caring responsibilities. Almost 9,000 people provide over 20 hrs of care – an increase of 21%
- ➔ We do not have updated local census information with regard to young carers to date. Census<sup>6</sup> data so far released reveals the number of five to seven year old carers in England has increased by around 80% over the last ten years to 9,371. The total number of children caring for parents, siblings and family members is up by 20% to 166,363 since the Census 2001 with nearly 15,000 providing more than 50 hours of care a week. The Children's Society<sup>7</sup> own analysis reveals this is likely to massively under represent the true picture.

---

<sup>4</sup> Census 2011

<sup>5</sup> Census 2011

<sup>6</sup> Census 2011

<sup>7</sup> Hidden from View, The Children's Society May 2013

[http://www.childrensociety.org.uk/sites/default/files/tcs/report\\_hidden-from-view\\_young-carers\\_final.pdf](http://www.childrensociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf)

## Equality, work and health

In individual and strategic planning for carers and young carers it is important to consider how their caring responsibilities can potentially unfairly limit their choices for wider opportunities. The Equalities review which contributed to the national strategy suggests that in order to offer carers more choice and control in balancing commitments and aspirations, and tackle inequalities, a strategy should:

- ➔ Tackle the barriers to achieving more equal outcomes that caring creates;
- ➔ Ensure equality of access to support for carers.

No two caring relationships are ever the same; however, grouping carers with shared areas of need ensures specific attention. For example, identifying and working specifically with older carers caring for a son or daughter with a learning disability can help relieve worry concerning the future and help the carer to be involved in long term planning.

While historically women were most at risk of social isolation, health problems and financial hardship due to caring, there are almost as many men with caring responsibilities today. Information and training must be gender targeted, as must support. Flexibility is essential in recognising diversity supported by services like the Carers Support Fund and, in future, more personalised services.

The rural nature of the county means that some carers face particular challenges. It is not unusual for families in rural Northumberland to be in excess of 15 miles from their GP surgery or other local amenities. It is often not practicable for public bodies to commission as wide a choice of services for people who live in remoter areas, and transport can also be difficult, particularly for people who are not able to drive. Social isolation can be a serious problem, affecting people's health and wellbeing and their access to networks offering support and advice. For some people in this situation, a solution may be to move to a market town or larger settlement and the availability of attractive and suitable housing options for older or disabled people who might benefit from doing this is vital.

Combinations of disadvantage including caring responsibilities often lead to a cycle of worklessness and ill health. As an illustration, a person who becomes a carer whilst still a child; this person is more likely to be a girl than a boy. We know that she is more likely than average to be economically inactive, and still a carer, as a young adult. She is therefore living on a low income and is at risk of social isolation and of developing mental illness.<sup>8</sup>

Many carers juggle work with caring and view their work as a vital part of their lives. It not only provides much needed financial security and a break from caring, but increased self-esteem and a valuable sense of identity separate from their role as a carer. There are over 1.5 million carers in England aged between 25 and 59 years. Half of these are under 45 years of age – prime working age.<sup>9</sup>

---

<sup>8</sup> Equality and Diversity in the North East region of England: a baseline study. D.Penn, J Shewell 2005

<sup>9</sup> *Carers at the heart of 21<sup>st</sup> century families and communities. National Carers Strategy 2008*

People who give up work to care face an immediate reduction in income and the loss of companionship at work. Social exclusion is a very real possibility. A break in employment may also damage promotion and development prospects, and re-entry into employment when caring responsibilities come to an end can be extremely difficult.

Carer Health is an issue: in addition to other disadvantage and exclusion, we know carers are also more likely than others to suffer from health problems themselves. The pressure of caring for someone can be extremely demanding physically, emotionally and mentally. Helping to keep carers healthy is crucial if they are to continue to provide this essential support. Some health problems may be a direct result of caring, some may be exacerbated due to the carer failing to focus upon their own health needs due to the often greater need of the person cared for. Many people with long term health needs themselves also have caring responsibilities. The health statistics in relation to carers are hard to compare over the last ten years because the question in the 2011 census changed. This census has revealed that 13% of carers providing over 50 hours of care a week are in 'bad or very bad health'. The Children's Society<sup>10</sup> own analysis reveals 2011 Census figures of young carers are likely to massively under represent the true picture and point out that young carers are one and a half times more likely to have a long-standing illness or disability or special educational need than their peers.

Northumberland has a very low black and minority ethnic population, 1.6%<sup>11</sup>. Carers in these families are therefore less supported or understood than in larger ethnic groups with support networks in other areas. There is a high risk that people do not always understand they might be entitled to support. There are also a lower proportion of refugees, asylum seekers and possibly lesbian, gay and bisexual people<sup>12</sup>. The experience of caring will differ according to the circumstances of the person cared for and cultural expectations and family structures within different communities.

## How have carers informed the strategy?

The strategy is the result of a lot of discussions with carers, the people they support, professionals and agencies – as well as careful review of information about local needs and services. Carer involvement has included:

- ➔ A Carers Event held in July 2012 involving carers and cross-agency professionals coming together to consider priorities and inform our strategy.
- ➔ Carers views through service and process evaluations and reviews e.g.
- ➔ A statement of commitment to carers developed with carers for the Marie Curie Delivering Choice Programme and adopted by Northumberland County Council in 2012.
- ➔ Ongoing feedback collated by Carers Northumberland through listening to carers individually and in groups to identify need.

---

<sup>10</sup> Hidden from View, The Children's Society May 2013

[http://www.childrenssociety.org.uk/sites/default/files/tcs/report\\_hidden-from-view\\_young-carers\\_final.pdf](http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf)

<sup>11</sup> Census 2011

<sup>12</sup> Equality and Diversity in the North East region of England: a baseline study. D.Penn, J Shewell 2005

- ➔ Feedback through the social care and health systems e.g. forums, complaints team, engagement events etc.
- ➔ Work with Young Carers and Parent Carers led by the Family and Children's Trust (FACT).
- ➔ Adult Social Care Outcomes Framework (ASCOF) Carers Survey 2012-13 (Northumberland).

## Our Values and Principles of Practice

Former carers who had supported family members and friends with end of life care worked with us as part of the Marie Curie Delivering Choice Programme in 2010 to develop an agreed way of working that recognises carers a '*partners in care*'. The resulting *Statement of Commitment to Family & Friends with a Caring Role within End of Life Strategies* is based on the views of these carers. The statement recognises and gives value to the important work that unpaid carers provide and is relevant to all caring situations, and in particular toward the end of a person's life.

The statement uses the term 'carers' in its broadest sense to include the most significant people in the life of the person needing support, including children and young carers. It is felt important to clarify with the person who they see in this role and to note that the carer is not always the "nearest relative".

In commissioning services we will recommend individual care providers embedded the principles of the statement within their service delivery culture and wherever possible demonstrate it is having a direct, positive impact on carers accessing their services.

### *Statement of Commitment to Family & Friends with a Caring Role*

#### **1. We will recognise and respect your role and expertise:**

- ➔ Listening to you and taking what you say seriously
- ➔ Recognising your expert knowledge and understanding of the person you care for.
- ➔ Understanding the emotional impact on you and other complexities of your caring role.
- ➔ Understanding and respecting the relationship you have with the person you care for.
- ➔ Understanding and recognising that caring roles can change and that people who need support can also have caring responsibilities for others.

#### **2. We will involve you in the care plan for the person for whom you care:**

- ➔ Including you in discussions and decisions that impact upon you
- ➔ Listening to your views at all stages while recognising that the things you need to know may be difficult for you to hear.

- ➔ Ensuring contingency plans are in place in case you are suddenly unable to provide support.
- ➔ Being proactive in ensuring confidentiality does not become a barrier to sharing information with you.

### **3. We will give you the information and advice you need to help you care:**

- ➔ Offer you information when and how you need it, in a format and language that is appropriate to each individual carer, recognising the often complex and high level of care you are providing.
- ➔ Whenever possible seeking to identify/provide you with a single point of contact and sufficient information to manage emergencies.
- ➔ Understanding knowledge and information about what happens at the end of life is also important to you.

### **4. We will recognise and respond to your own needs:**

- ➔ Understanding your other commitments outside caring, such as childcare, work or education. Helping you find solutions which help you in your caring role.
- ➔ Always asking and never assuming you are coping.
- ➔ Recognising that your needs don't end at the same time as the person for whom you care.
- ➔ Understanding you have legal rights and helping you access carer information and support services.
- ➔ Providing you with practical information and training to help you care safely and effectively.

### **5. We will recognise your role if you are a child or young person (under 18):**

- ➔ Recognising that you provide support that is seldom identified.
- ➔ Understanding the impact of the situation on your life
- ➔ Making sure you have support to help you in your role as a carer
- ➔ Making sure you can make choices about what you do as a carer
- ➔ Making sure you have the information you need
- ➔ We will not ignore you.

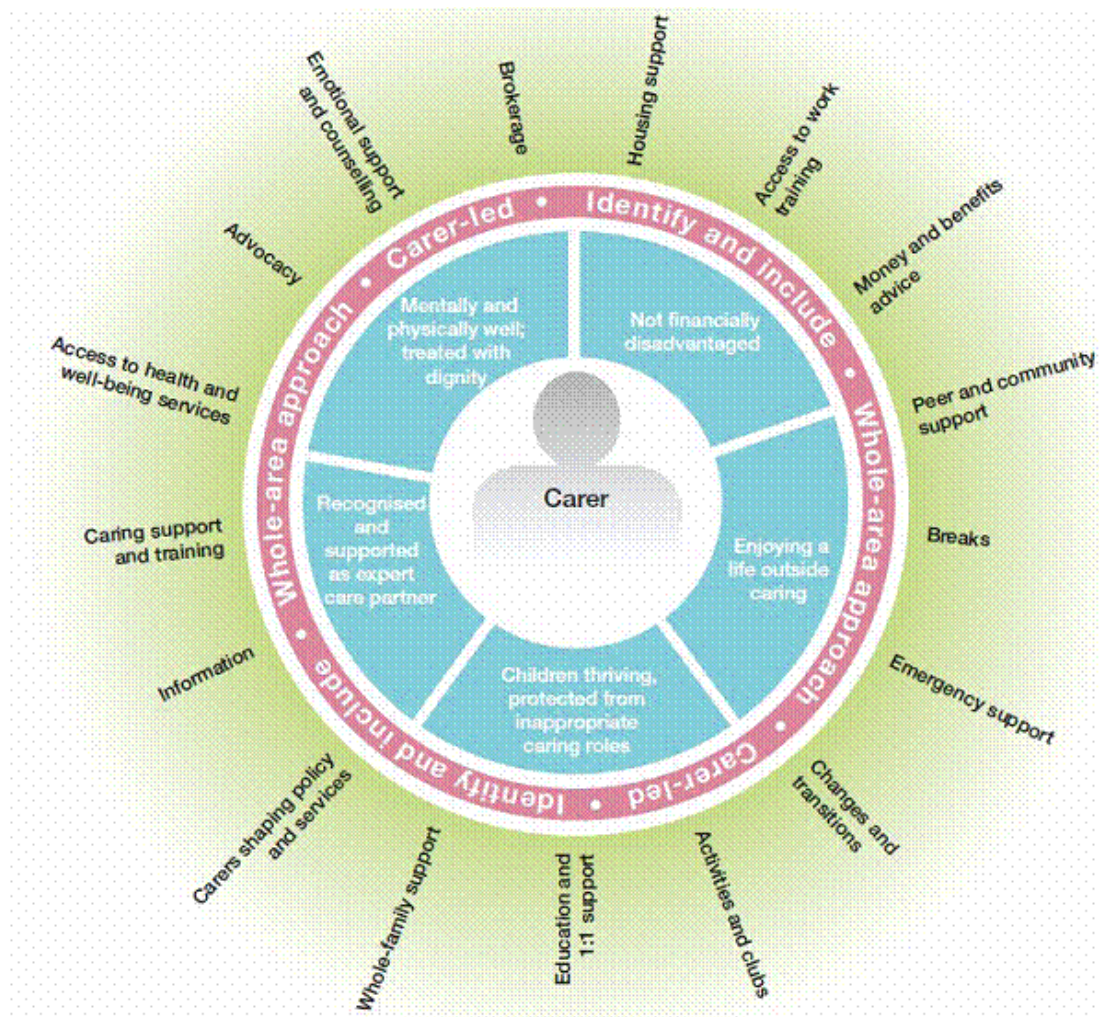
## The Model of Comprehensive Carer Support

We have worked to a local carers' strategy for the last twelve years, leading to many positive changes in the support for carers in the county. In developing a new joint strategy and a more robust joint commissioning plan for carers from 2013 we have consulted with carers in Northumberland and brought together an overview of the range of interventions and services currently available.

To help us to take stock and assess where we are in supporting carers we have based our local approach on a national model of comprehensive carer support, The Carers Hub.

<http://www.carershub.org/hub>

The five segments on the inner circle of the Carers' Hub represent the National Carers' Strategy outcomes:



We have used the hub to carry out an up to date assessment to establish:



- ➔ what services are currently available
- ➔ which of the National Carers' Strategy outcomes are being met
- ➔ which groups are being served
- ➔ what local carers and their families want.

## Using this model to map services in Northumberland

Each intervention in the model was defined, mapped in the local area and a summary of how fully services meet the needs of all carers who may need was then made. Following each definition we have gathered case examples of ways in which different providers are meeting at least an aspect of each type of service both locally and nationally – these case examples do not in themselves give a full picture but are used as illustrative examples only.

The services are categorised into the following groups –

- Primary – services directly to or for the carer
- Secondary - support for the carer and cared for
- Tertiary – services for cared for e.g. holiday/break for cared for - which by default gives the carer a break
- Open services – services that are available to both the carer and the cared for, although not specifically designed for carers or the cared for and available to a significantly wider cross section of the population.

The mapping does not aim to judge quality of services that are available but is a reflection of the range of support available and to which groups of carers. It will help to identify gaps and suggest potential service developments. The findings of this mapping influence the implementation of the carers' strategy and annual action planning and can be viewed in full at <http://www.northumberland.gov.uk/carers>

## Services in Northumberland

The main support services for carers in Northumberland are provided through:

- ❑ The statutory service providers within Northumberland, which includes adult and children's social care providing an opportunity for the needs of the carer and the person cared for to be assessed and, when eligible, for services or personal budgets to be arranged. This also includes community and hospital based health services. These services support, in effect, a minority of the estimated 36,000 carers in Northumberland
- ❑ The voluntary and community sector including Carers Northumberland and other condition or age specific organisations who are in a position to respond flexibly to carer needs and offer information and services to carers whether they are known to statutory services or not.

- ❑ Mainstream services available to the whole population, such as leisure, libraries, CAB and other information sources including local or national web based information.

People providing unpaid care or support rarely identify themselves as a 'carer' until someone else, often a professional or another carer, uses the term. They therefore often don't access information, support or benefit entitlement until they have been caring for some time or until they ask for help for the person they care for. It is therefore imperative that all professionals understand their role in identifying carers early.

The primary concern for most carers is around the health and wellbeing of the person they care for and appropriate quality services for that person. It is therefore equally imperative that professionals recognise the impact of caring upon the carers own health and wellbeing and encourage carers to also think about their own needs.

## Key commissioning priorities

### Priority 1: Recognition and Information

#### What have carers been telling us?

- ➡ The health and wellbeing check is helpful in preparing for a carers needs assessment
- ➡ clearer communication lines between professionals are needed to avoid duplication and/or black holes;
- ➡ Continue to promote the range of services in information available to carers.
- ➡ Carers Northumberland is an important source of information for carers
- ➡ In Northumberland Carers Survey 2012-13 85% of carers said they either had not needed to look for information or had found it fairly easy to find.
- ➡ In Northumberland Carers Survey 2012-13 88% of carers who accessed information found it had been helpful.
- ➡ 25% of carers surveyed by Carers Northumberland in 2012 said they have suffered physical or emotional abuse, often as a result of the condition of the person cared for.

#### Planned actions:

1. Ensure carer needs assessments are an integral part of the Self Directed Support process making it easier for carers to access support.
2. Promote and support a one stop information point for carers (Carers Northumberland) and ensure that carers are signposted to other relevant information they need.
3. Improve identification of carers and access to information in acute hospital care.
4. Better identify isolated carers looking after housebound patients with complex needs.
5. Work with GP practices to increase awareness, identify carers and ensure carers know how to access support.

6. Review existing information for carers e.g. Friend and Family Carers Guide, to ensure it is up to date and fulfils carer requirements and to identify gaps in information.
7. Maintain and distribute a carer resource guide to inform carers and professionals.
8. Increase the profile of young carers identified in adult services, support adult workers in being able to assess and understand their needs to maximise life chances.
9. Improve the identification of young carers by linking with school nurses to raise the profile of young carers in schools.
10. Establish a community of interest around young carers to ensure that information is available to support those working with children and young people in identifying and responding to their needs.
11. Pilot a methodology in one of the Academies around Excellence in working with young carers which would have a sustainability model built in to roll out across the county.
12. Ensure a carer focus in professional learning and development programmes.
13. Include carer identification as a key target within all future strategies.
14. Introduce protocols that fully recognise the role of people with disabilities as carers i.e. mutual caring.
15. Share best practice to ensure carers are supported by all agencies.
16. Implement the Joint Working Guidance, as ratified by both the Children's Safeguarding and Safeguarding Adults Boards.
17. Recognise the potential role of the carer in safeguarding as alerter, intentional or non-intentional abuser and as vulnerable to abuse themselves to inform policy and practice.

## Priority 2: Support

### What have carers been telling us?

- ➔ The carer support fund works well, providing a good range of flexible breaks
- ➔ More "hands on" support is needed for young carers.
- ➔ Improved hospital discharge co-ordination should be a priority.
- ➔ There is some good support for families to help with managing tenancies. But housing providers need to be aware when there's a carer in the house and work to consider/support the whole family; housing needs to be involved at a strategic level for carers.
- ➔ Carers Northumberland and other condition specific voluntary sector organisations provide a good range of peer support.
- ➔ Priorities are to maintain what we've got in Northumberland, decide how to maximise services and information through partnership working (and avoid duplication), with shared aims for accessible support and information for carers.
- ➔ In Northumberland Carers Survey 2012-13 88% of carers said that they were able to spend time as they want, doing things they value or enjoy, however, 64% would still value more time to themselves. 12% said they don't do anything they value or enjoy.

- ➔ The number of carers having a Carers Emergency Card has increased year on year, currently 629 carers are registered with the scheme. The Red Cross have provided a sitting service when needed e.g. when carer has been in A&E or for carers' hospital appointments and emotional support in crisis.

### Planned actions:

1. Provide clearer information about the breaks opportunities available to carers, including eligibility for support.
2. Increase the number of carers receiving a personal budget.
3. Audit information provided through the hospital discharge pathway to identify gaps.
4. Improve flexibility and choice around short breaks through innovation and development e.g. shared lives scheme, listening to and adapting to the needs of people cared for requiring alternative care.
5. Ensure emergency planning for carers is integral to support planning.
6. Continue to provide specialist support to Young Carers through specialist groups across the county.
7. Use the CAF (Common Assessment Framework) to identify the support needs of Young Carers and to respond on an individual basis.

## Priority 3: Health and well-being

### What have carers been telling us?

- ➔ The carers wellbeing check and carers assessment are seen a way to access good emotional support and encourage carers to think about their own health.
- ➔ There are a number of organisations valued by carers for providing emotional support, organisations cited in consultation include Carers Northumberland, Macmillan Nurses, community hospices, Alzheimer's Society and Escape family support.
- ➔ More carers are recognised by their GP and feel supported but some GP Practices could do better.
- ➔ Access to counselling for carers is limited.
- ➔ Carers need help after caring ends.
- ➔ 25% of carers surveyed by Carers Northumberland in 2012 said they have suffered physical or emotional abuse, often as a result of the condition of the person cared for.
- ➔ In Northumberland Carers Survey 2012, 92% of carers said they had no worries about their personal safety; 8% had some worries with 3 people admitting they were extremely worried.
- ➔ In Northumberland Carers Survey 2012, carers were asked whether they are able to look after themselves in terms of getting enough sleep and eating well. 66% said they look after themselves, 20% sometimes can't look after themselves well enough and 12% said they felt they neglected themselves.
- ➔ 64% of carers surveyed in Northumberland had some sort of health problem themselves. Of the overall group 52% were caring for more than 50hrs a week.

## Planned actions:

1. Extend the use of the Carers Wellbeing Check to all practitioners in touch with carers, thereby encouraging carers to consider their own health needs and access GP services.
2. Improve access to carer information in acute healthcare settings and ensure carers are given the information they need to care safely and effectively as part of discharge planning.
3. Improve access to currently commissioned counselling services, identifying barriers to carers in accessing these services.
4. Encourage GPs to identify people with a caring responsibility and assess their needs, including risk of depression.
5. Provide training to carers in basic caring skills, especially moving and handling to reduce injury and harm.
6. Ensure all organisations commissioned to work with carers are aware of and work to the Statement of Commitment to Carers.
7. Increase access to support for carers when caring ends or changes recognising the emotional impact at times of transition.

## Priority 4: Financial Wellbeing (access to work and benefits)

### What have carers been telling us?

- ➡ Various VCS organisations including WRVS, CAN; Dawn and CAB were highlighted as being very good.
- ➡ We need to make sure carers get information about benefit entitlement early.
- ➡ Carers also need to understand the benefits system for the person they care for so that they can advocate on their behalf.
- ➡ In Northumberland Carers Survey 2012-13 35% of carers said they were juggling work with care and of those only 15% felt supported by their employer.
- ➡ Carers in the Dementia Forums feel information about legal issues, including wills and enduring power of attorney needs to be timely and is essential.
- ➡ Carers of younger people with complex needs rated training on the Mental Capacity Act in 2013 excellent and empowering and would like more carers to benefit.

### Planned actions:

1. Work with relevant agencies to provide support with access to leisure, lifelong learning, volunteering, skills and work opportunities.
2. Work with employers to promote carer-friendly employment practices in the county.
3. Work in partnership with Jobcentre Plus to help carers access training and work.
4. Ensure carer assessment processes and training highlight the carers need or wish to work.
5. Increase the take up of Attendance Allowance in the county and promote Carers Allowance.

6. Increase access to welfare rights and legal training for service users and carers to empower them to manage financial and legal affairs better and maintain independence.
7. Ensure all carers are aware of and are supported in accessing training and employability support through the ESF<sup>13</sup> Family Support Programme.

## Priority 5: Quality services

### What have carers been telling us?

- Good respite opportunities are felt to be available and personal budgets are allowing people to buy items they really want. However there are thought to be problems around respite opportunities being limited by personal finance.
- The carers resource guide provides information of breaks available, activities to be enjoyed include specialist autism friendly cinema screening, council leisure facilities and activities provided by the Calvert Trust. However there is stigma around young carers who are sometime reluctant to take up services.
- Leisure services for people with disabilities help carers have a break and there is more information available about mainstream services.
- In Northumberland Adults Social Care User Survey 2012-13 88% of people who use services said that those services have made them feel safe and secure while overall 91% responded that they were extremely, very, or quite satisfied with the care and support services they receive.
- In Northumberland Carers Survey 2012-13, 7% said they had received no services or support in the last 12 months for the carer and person cared for, 70% were extremely, very or quite satisfied with the support and services they had received. 23% were dissatisfied.
- Of the total carers sent a Northumberland Carers Survey 2012-13, 78% of the people they support were in receipt of a personal budget managed by the Local Authority via Direct Payments. 2.2% of the survey sample had received a personal budget for carer services.

### Planned actions:

1. Develop coordinated whole family support through shared protocols and better practice in referral, assessment and personalised support planning.
2. Give carers more choice in short breaks, through access to the Carers Support Fund<sup>14</sup> and through personal budgets.
3. Improve support planning for carers to deliver more flexible support that sustains care and prevents crisis through good support planning and emergency plans as part of routine practice.
4. Target resources to priority groups of carers: young carers, older carers, mutual carers, carers of people with dementia.
5. When commissioning services for or support planning with people with disabilities take into consideration the impact on the carer.

<sup>13</sup> European Social Fund

<sup>14</sup> Delivered through Carers Northumberland

## Priority 6: Having a voice

### What have carers been telling us?

- ➔ Northumberland Carers Survey 2012, 39% of carers felt they had been involved and consulted as much as they wanted to be in discussions about the support or service provision to the person cared for. 28% said they usually felt involved or consulted and only 4% felt they were never involved or consulted.
- ➔ We need to promote better communication between professionals and clients whether about possible options or medications etc. respecting that both carers and cared for should have an equal voice in any decision making process and be listened to.

### Planned actions:

1. Continue to involve carers at a strategic level in the implementation of the Carers Strategy.
2. Influence provider organisations to ensure carers have influence within strategic planning and monitoring of services that support carers and the people they care for. For example, carer representation on Northumbria Healthcare Quality Council to influence change in health pathways; Carer representation on Safeguarding Board, Learning Disability Board etc.
3. Work in partnership with Carers Northumberland and other agencies working with carers to ensure feedback from events, forums and surveys are used effectively and transparently.
4. Ensure the experience of carers is used in all carer training of staff groups, where possible through direct involvement, and integrate a carer focus into all other relevant training.
5. Make sure procedures in health and social care guarantee, when appropriate, that carers are routinely offered involvement in care planning, discharge and ongoing help and support.
6. Increase carer awareness of safeguarding reporting of people who may be neglected, abused or taken advantage of.
7. Work with Healthwatch to ensure the voice of carers is heard, especially hidden carers.
8. Ensure that as part of the funding agreement with voluntary sector organisations consultation with Young Carers is integral to the process.

## Joint Social Care and Health Commissioning Plan

A joint social care and health commissioning plan accompanies this document and includes a detailed action plan to support the implementation of the strategy. The action plan is regularly updated and formally reviewed annually. All documents can be viewed online at <http://www.northumberland.gov.uk/carers>

## Appendix1: Policy Related Documents

(For summaries & information, full explanation of the law – [www.direct.gov.uk](http://www.direct.gov.uk) )

**The NHS and Community Care Act 1990** requires that local authorities involve families and carers when making plans to assist adults who are vulnerable.

**The Carers (Recognition and Services) Act 1995** introduced the right of a separate assessment, if a person was being assessed under the 1990 Community Care Act, creating the building block for the following Carers' Acts.

**The Carers and Disabled Children Act 2000** gives carers over the age of 16, the right to an assessment, irrespective of whether the person they support has been assessed or is receiving services. It also gives local authorities the power to provide services direct to the carer to meet their assessed needs and enables carers to apply for direct payments to meet their own needs.

**The Carers (Equal Opportunities) Act 2004** gives local authorities the duty to inform carers of their right to an assessment; give consideration to the wishes of a carer to work, to undertake education or training, or to engage in leisure activities; and the power to ask assistance from other authorities in planning the provision of services to carers.

**The Employment Act 2002** gives working parents of disabled children under 18 the right to request flexible working.

**The Work and Families Act 2006** extended the right to request flexible working to employees who care for adults.

**Disability Discrimination Act(s)** recognises the right of people in society to equal citizenship (including carers and people they care for and support).

**Our Health, Our Care, Our Say: A New Direction for Community Services, White Paper 2006** announced a 'New Deal' for carers including setting up a national helpline, training for carers, funding for emergency planning and the revision of the National Carers' strategy.

<http://www.dh.gov.uk/en/Healthcare/ourhealthourcareoursay/index.htm>

**Carers at the heart of 21<sup>st</sup> century families and communities 2008** is a new national carers' strategy that outlines the Governments vision for carers in the next 10 years.

[http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH\\_085345](http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345)

**NHS Constitution 2009** builds on the NHS commitments to carers in the National Carers' strategy.

<http://www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm>



In addition the following relate to specific 'customer' groups:

**Every Child Matters 2003**

<http://www.everychildmatters.gov.uk/>

**Mental Health National Service Framework 1999**

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4006057](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006057)

**Hidden Harm**

<http://drugs.homeoffice.gov.uk/publication-search/acmd/hidden-harm?view=Binary>

**Long Term Conditions National Service Framework 2005**

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4105361](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361)

**National Dementia Strategy**

<http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm>

**Older People National Service Framework 2001**

<http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NSFforOlderPeopleandsystemreform/index.htm>

**Valuing People Now: from Progress to Transformation**

<http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Learningdisabilities/index.htm>

**Putting people first: a shared vision and commitment to the transformation of adult social care**

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_081118](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118)

## Appendix 2: Glossary

<b>CCG</b>	Clinical Commissioning Group
<b>NCC</b>	Northumberland County Council
<b>NHCT</b>	Northumbria Healthcare NHS Foundation Trust
<b>NTW</b>	Northumberland, Tyne and Wear Mental Health NHS Foundation Trust
<b>GP</b>	General Practitioner
<b>CQUIN</b>	Commissioning for Quality and Innovation (NHS payment framework)
<b>LDU</b>	Learning Development Unit (Adult Services)
<b>CAF</b>	Common Assessment Framework
<b>LTC Rehab</b>	Long Term Conditions Rehabilitation